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April 5, 1989

PROPOSED PRESIDENTIAL ARTICLE
"EXCEPTIONAL PARENT" MAGAZINE

I am writing in response to your editorial letter "Dear Mr. President" which appeared in the March 1989 issue of Exceptional Parent. You have clearly stated my commitment to those of our citizens with disabilities and appropriately highlighted the progress our country has made in integrating people with disabilities into the mainstream of American life. I wish to take this opportunity to highlight those issues on which my Administration will continue to focus its efforts and to reiterate the commitment of this Administration to those with disabilities.

Today, many individuals with mental and physical disabilities are active participants in typical school, work and community activities. They share in the ordinary routines of learning and living essential for all. Yet, the challenge remains to help all people with disabilities, including those with the most challenging needs, to beomce integral parts of their communities. To accomplish this goal, we must encourage the belief and understanding that people with disabilities are enthusiastic, valuable members of our society who want to contribute to their country and to make choices about their lives.

Educating disabled children in the least restrictive environment possible is one way to achieve this foundation and it

is the mandate of the Education of Handicapped Children Act (PL 94-142). Educational and economic opportunity is the foundation for success that will make all disabled Americans vibrant threads in the fabric of their communities. This nation is committed to the notion that schools are for <u>everybody</u> and should be measured by their success in serving <u>all</u> students, including those with disabilities. The qualities and practices necessary to make integration work for students with disabilities are the same qualities and practices that characterize effective schools for all children.

which qualities & practices?

America's schools are responsible for preparing students for a productive, satisfying future. For the typical student, success is measured in outcomes such as meaningful work, a healthy, safe place to live, and personal fulfillment, which includes a a social network of family and friends. These goals are equally valid for students with disabilities. Education in an integrated environment assists in preparing students to live in integrated communities as adults.

However, our efforts to insure integration of persons with disabilities into our communities will remain unfinished as long as there are talented, determined unemployed disabled Americans. They want to be a part of the economic mainstream because work enhances self-esteem and contributes to the overall quality of life. We want to continue the emphasis on preparing special education students for transition from school to employment. Young people with disabilities continue to experience high levels

of unemployment despite increased educational opportunities available to them under P.L. 94-142. At the local level, school systems and adult service systems must continue to work with young people, parents, and employers to develop appropriate transition plans and services for each student that support their entry into the work world.

To expand employment opportunities for those with severe diabilities, we are encouraged by the success of "supported employment" nationally. Through supported employemnt, persons with disabilities so severe that they have never been able to work in competitive employment, are placed into real work settings, trained at the job site, and provided long-term support services. Thousands of people, a few years ago considered unemployable because of their disabilities, now hold paying jobs. Research and practice show that supported employment is feasible, desirable, and cost-effective. Companies throughout the country that rely on a diminishing supply of younger workers for their work force are hiring individuals through the supported employments in increasing numbers. Programs like these, which put the productive capacity of persons with disabilities in the American economy must be encouraged and expanded.

ok to put quote marks?

Can we say this?

But as important as government and community help is to integrating those with disabilities into American life, the family still remains at the heart of the solution. People with disabilities need to participate in the same settings as others and support and involvement are especially critical for those

or will this raise funding questions?

with disabilities. The positive contributions of individuals with disabilities to their families must be underscored. Strategies for supporting families should enhance the dignity of individuals with disabilities by recognizingg their positive contributions. Indeed, many of our policies and regulations need to be examined to assure incentives for family cohesiveness. The key is to support not supplant the family.

As we move into the 1990s, significant challenges and opportunities face our country in regard to those with disabilities. While some people may have special needs and present special challenges in integrating them into the community. they are, first and foremost, human beings with human needs. They need a decent place to live, meaningful activities, relationships with other people -- and most of all, respect and dignity. I pledge strong leadership as we move forward to make these mutual goals a reality.

# # #

FINAL

PRESIDENTIAL RESPONSE
"EXCEPTIONAL PARENT" MAGAZINE

I am writing in response to your editorial "Dear Mr. President" which appeared in the March 1989 issue of Exceptional Parent. You have clearly stated my commitment to those of our citizens with disabilities and appropriately highlighted the progress our country has made in integrating people with disabilities into the mainstream of American life. I wish to take this opportunity to highlight those issues on which my Administration will continue to focus its efforts and to repeat my dedication to those with disabilities.

Today, many individuals with mental and physical disabilities are active participants in typical school, work and community activities. They share in the ordinary routines of learning and living essential for all. Yet, the challenge remains to help all people with disabilities, including those with the most challenging needs, to become integral parts of their communities. To accomplish this goal, we must encourage the belief and understanding that people with disabilities are valuable members of our society who want to contribute to their country and to make choices about their lives.

Educating children with disabilities in the least restrictive environment possible is one way to achieve this foundation and it is the mandate of the Education for All Handicapped Children Act (PL 94-142). Educational and economic opportunity is the foundation for success that will make all

Americans with disabilities vibrant threads in the fabric of their communities. This nation is committed to the notion that schools are for everybody and should be measured by their success in serving all students, including those with disabilities.

America's schools are responsible for preparing students for a productive, satisfying future. For the typical student, success is measured in outcomes such as meaningful work, a healthy, safe place to live, and personal fulfillment, which includes a social network of family and friends. These goals are equally valid for students with disabilities. Education in an integrated environment assists in preparing students to live in integrated communities as adults.

However, our efforts to ensure integration of persons with disabilities into our communities is unfinished as long as Americans who are disabled remain unemployed. They want to be a part of the economic mainstream because work enhances self-esteem, because they want to contribute to their country's productivity and global competitiveness, and because they recognize that their talents are needed. We want to continue the emphasis on preparing special education students for transition from school to employment. Young people with disabilities continue to experience high levels of unemployment despite increased educational opportunities available to them under P.L. 94-142. At the local level, school systems and adult service systems must continue to work with young people, parents, and

employers to develop appropriate transition plans and services for each student that support entry into the work world.

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But as important as government and community help is to integrating those with disabilities into American life, the family still remains in the center. People with disabilities need to participate in the same settings as others and support and involvement are especially critical for those with disabilities. Strategies for supporting families should enhance the dignity of individuals with disabilities by recognizing their contributions. Indeed, many of our policies and regulations need

to be examined to ensure incentives for family cohesiveness. The key is to support -- not supplant -- the family.

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# # #

EXCEPTIONAL PARENT®

Stanley D. Klein, Ph.D.
Editor

Parenting your child with a disability

1170 Commonwealth Avenue
Boston, Massachusetts 02134
(617) 730-5800

February 28, 1989

Mr. M. Fitzwater
Office of the Press Secretary
The White House
1600 Pennsylvania Avenue
Washington, D.C. 20500

Dear Mr. Fitzwater:

I have enclosed a copy of the editorial, "Dear Mr. President," which will appear in our March issue (scheduled to appear in a few days), because we would be honored to receive a response from the President in time for our April issue. We will even settle for our May issue since we are well aware that your office is a busy one.

EXCEPTONAL PARENT is a consumer education magazine for parents of children with disabilities. We distribute 45,000 copies of each issue throughout the USA. Based on survey data, we estimate that 230,000 people read each issue of our magazine. I have taken the liberty of enclosing recent copies and some other materials about the magazine for your review--including the October issue in which we published the candidates' statements noted in the current editorial.

It is clear to me, as well as to others I have spoken with, that President Bush's specific mentioning of people with disabilities has already had a significant impact on children and adults with disabilites and their families. That is why we have written this editorial and why we would be pleased to have an official response.

As soon as we receive our first copies of the March issue, I will send you some copies for your review. Thank you.

Sincerely yours,

Stanley D. Klein

Stanley D. Klein, Ph.D., Editor

sdk/s; enc

OK/GP

Maxwell J. Schleifer, Ph.D.
Stanley D. Klein, Ph.D.
Exceptional Parent
1170 Commonwealth Avenue, Third Floor
Boston, Massachusetts 02134

Dear Mr. Schleifer and Mr. Klein:

I am writing to thank you for your editorial addressed to me in the March 1989 issue of Exceptional Parent and for your thoughtful letter. I am pleased to learn that my public concern for the problems of children and adults with disabilities has already made an impact on them and on their families. I will certainly continue to speak out on these issues in the future.

Having listened to many people with disabilities over the past several years, I share their desire to do more to bring them into regular school, work, and community activities-- particularly the most severely disabled. It is to everyone's advantage that these young people move into the economic mainstream and prove to the next generation what their currently employed counterparts have already proven: that disabilities can often become incentives to greater efficiency and more notable achievement.

I also want to see more programs and policies that give all people with disabilities access to every activity in our society--to the mainstream educational system, to public accommodations, to public transportation. As you and your readers know, much has already been done in these areas, but much work yet remains.

Since these are matters on which there is considerable bipartisan agreement, I look forward to cooperating with Congress in exploring ways in which the Federal government can help to initiate further progress. I am hopeful that we will all be working together to achieve the common goals we clearly share.

Thank you again for your editorial and for your letter.

See p. 12

- BOTH LETTERS OR ONLY ONE?
- BUURB?

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MARCH 14, 1989

TO: DAVE DEMAREST

FROM: MARLIN FITZWATER

FOR ACTION.

Patty Smith
Office of Spec Ed + Rehab Serv.
330 C St SW
Room 3006

FAX: 732-1252

EXCEPTIONAL PARENT
Parenting your child with a disability

From the Desk of
Stanley D. Klein, Ph.D.
Editor

Dear Mr Fitzwater

Here is the magazine with our letter to the President on page 9.

We look forward to receiving a response.

Thank you

Stan Klein

See p. 9

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Exceptional Parent Mag.

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EXCEPTIONAL PARENT®

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Editor

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Sincerely yours,

Stanley D. Klein

Stanley D. Klein, Ph.D., Editor

sdk/s; enc

Dear Mr. President,

During your campaign, you demonstrated a keen awareness of the issues confronting children and adults with disabilities and their families.

In your statement as a candidate published in October's EXCEPTIONAL PARENT you wrote that "without aggressive public and private support, people with disabilities will not be able to achieve their highest priority, namely the independence necessary to achieve control over their own lives and integration into the mainstream of American life."

You also noted that "we must include people with disabilities and their parents in the process (of providing meaningful access to all aspects of society) to ensure that their real needs are addressed." Further, you pledged to "expand the number of persons with disabilities and parents of persons with disabilities to key positions in my administration."

You made it clear that these are not radical goals. In the campaign you directly addressed the concerns of people with disabilities in your acceptance speech at the Republican National Convention and during the second Presidential debate. You demonstrated that you are willing to remind all of our citizens that meeting the needs of everyone with disabilities is an important part of our national agenda. After the election, you continued to demonstrate your personal interest and concern when you spoke at Gallaudet College using a sign language interpreter and when you appointed a committee to assure access to the Inaugural events for all Americans.

Now, as President, you can provide dynamic leadership needed to move our country towards the goals you support.

Since 1975, the Federal government has played a significant role in dramatically improving the lives of children and adults with disabilities and their families. The Education of All Handicapped Children Act (P.L. 94-142) has revolutionized the opportunities for youngsters to grow to become self-sufficient adults. Today, after more than a decade of implementation of that law, children and young adults with disabilities are involved at all levels of the educational systems. The benefits of educational programs for children with disabilities and their families are now being extended to the preschool years.

At the other end of the educational spectrum, Federal leadership has also encouraged the growth of programs that help youngsters make the transition from school to the adult world of work.

Last year, important new legislation — the Technology Related Assistance for Individuals with Disabilities Law of 1988 (P.L. 100-1407) — was passed and will be implemented in the current year. This law can enable individuals of all ages with disabilities to function more independently through the provision of assistance, technology, devices, and services.

Federal legislation (P.L. 99-506), passed in 1986, ensures technological access for all persons with disabilities to computers and other electronic office equipment in places of Federal employment. This program can serve as a model for employers in the private sector.

Two important pieces of legislation that need to be acted upon by the Congress already have considerable bipartisan support. The "Medicaid Community Quality Services Act" proposes the use of Medicaid to fund community and family support services as an alternative to the institutionalization of children and adults with disabilities. This bill also supports job training, respite care and other programs that help citizens with developmental disabilities to live in their own communities. The "Americans with Disabilities Act" was introduced in Congress in 1988 with the intent of prohibiting all discrimination on the basis of disabilities.

Federal laws already enacted and those proposed cannot succeed without strong leadership by the Executive branch of government. You know that each law requires adequate funding and consistent Federal monitoring so that the expanding opportunities can be available to citizens with disabilities of all ages wherever they and their families reside. Your administrative appointees to the critical Federal offices that develop and support the various Federal programs and services need your consistent support and leadership so they can carry out your policy commitments to people with disabilities and their families.

We look forward to your Administration taking the initiative to see to it that the American values of individual freedom of choice and involvement in the social, political and economic mainstream are applied to programs for individuals with disabilities. We believe that the gains our society has already made provide you and your Administration with the unique opportunity to complete this long overdue task.

We are prepared to work with you towards these goals by continuing to inform our readers of the activities of the relevant Federal government agencies and programs and by encouraging our readers participation in the democratic process. We wish you well.

Marshall J. Schleifer

Stanley D. Klein

Founders and Editors of EXCEPTIONAL PARENT

George H. Bush

The vast majority of the 36 million Americans with disabilities believe that their lives have improved in the past decade. Attitudes toward people with disabilities are changing in a positive direction and more people with disabilities than ever before are being educated. These are some of the findings of the first comprehensive survey of people with disabilities, conducted by Lou Harris and Associates and released in 1986. But I firmly believe, and the survey also indicated, that without aggressive public and private support, people with disabilities will not be able to achieve their highest priority, namely, the independence necessary to achieve control over their own lives and integration into the mainstream of American life.

By speaking with experts, with people with disabilities, and with parents of children with disabilities from around the country, I have learned much more about the needs of disabled individuals. I understand what people with disabilities strive for -- independence, control of their own lives, and integration into society. Many of the disabled I have met with have major responsibilities in local and national organizations such as The National Council on Independent Living, National Parent CHAIN, Capitol People First of Sacramento and the Assoc. on Handicapped Student Service Programs in Post-secondary Education, which are all run by and for people with disabilities. I am proud that from the start I have been able to speak directly with people with disabilities and the parents of children with disabilities, bypassing the intermediaries.

"We must develop programs and policies that promote independence freedom of choice and productive involvement in the social and economic mainstream."

These individuals made it very clear that those in the disability rights movement have two critical goals: the right of people with disabilities to control their own lives and make meaningful choices; and, the right to be integrated into all aspects of society. As far as education, the Republican Platform includes a commitment to protect the rights established under the Education for All Handicapped Children Act, which mandates a free, appropriate public education for all children with disabilities.

These goals may sound revolutionary in regard to the treatment of people with disabilities; but they are not radical in relation to the American values of individual freedom of choice and involvement in the social, political and economic mainstream. Although children and adults with disabilities have made many gains in the last decade, the stark fact remains that unnecessary segregation and exclusion of people with disabilities continues. As a result, disabled adults and families with disabled children suffer from stress, dependency and isolation.

We must remember that we are addressing a large and significant percentage of Americans. The Harris survey established that over 36 million Americans have disabilities; nine million of these Americans are under the age of 16. Forty percent of all adults with disabilities did not finish high school -- three times more than non-disabled individuals. In 1984, 50 percent of all adults with disabilities had household incomes of $15,000 or less. Among non-disabled persons, only 25 percent had household incomes in this wage bracket. With respect to employment, only one in four persons with disabilities works full time, another 10 percent work part time. There are at least eight million unemployed individuals with disabilities who want to work but need help finding employment. The statistics consistently demonstrate that people with disabilities are the poorest, least educated and the largest minority in America.

We must develop programs and policies that promote independence, freedom of choice and productive involvement in the social and economic mainstream. This does not merely mean employment. It also means access to the mainstream educational system, to public accommodations, to public transportation -- in other words, meaningful access to all aspects of society. Further, we must include people with disabilities and their parents in the process to ensure that their real needs are addressed.

The stakes are enormous. On the cost side, the National Council on the Handicapped states that current spending on disability benefits and programs exceeds $60 billion annually. Excluding the millions of disabled who want to work from the employment ranks costs society literally billions of dollars annually in support payments and lost income tax revenues. On the benefit side, the United States is now beginning to face labor shortages as the baby boomers move through the work force. People with disabilities offer a pool of talented workers whom we simply cannot afford to ignore, especially in connection with the high tech growth industries of the future.

During the past six years, I have advocated the appointment of persons with disabilities and parents of persons with disabilities to major posts in the federal government. As president, I will expand the number of persons with disabilities and parents of persons with disabilities appointed to key positions in my administration.

Moreover, I pledge that my administration will do away with "Hire the Handicapped Week" and replace it with federal legislation that gives people with disabilities the same protection in private employment that is now enjoyed by women and minorities.

Bush continued p. 14

MICHAEL S. DUKAKIS

personal assistance services to support personal independence, sustain the integrity of families and open avenues of employment. We can identify new and effective ways to reach out to persons with the most severe disabilities so that they too can enjoy the participation.

I have further supported the principle of self-determination of people with disabilities to leadership positions in key state agencies. I will continue to support the development of a strong national network of independent living centers. I will actively recruit people who have disabilities into all levels of government and public policy making.

For children with disabilities, their families are the major source of financial and emotional support. Families need and deserve far more assistance – respite care, parent training and help in accessing and coordinating services.

People in need should be able to count on the federal aid to which they are entitled. The current administration tried to throw hundreds of thousands of people with disabilities off the Social Security rolls without due process. In Massachusetts, I ordered a moratorium on these cuts and created a process that became the model for national legislation to prevent recurrence of this grave injustice.

Together, we can build a new future for American citizens with disabilities: a future of dignity, security and equal opportunity -- a future that will demonstrate that citizens with disabilities are full partners in society and equal partners in building a foundation of equality for all. ♦

GEORGE H. BUSH

In order to assume that every American who wants a productive job in the private sector has a job, I will continue to support initiatives to:

- Ask the private sector to work more aggressively in hiring people with disabilities, using my office to educate employers about the statistics showing clearly that, other things being equal, disabled employees perform above average.
- Train people with disabilities for jobs that really exist where they live.
- Work with Congress to eliminate disincentives that discourage disabled persons who wish to work from working.
- Improve transportation and work place accessibility for existing facilities and insist on accessibility for all new construction.
- Support independent-living centers to help disabled persons with the transition to independence.
- Urge private insurers to find ways to include, not exclude workers with disabilities in their programs.

Individuals with disabilities are not a small, uniform minority with narrow interests. The disabled community includes every race, culture, age, sex and economic class. Membership is open to all and most of us who live our full life span will join this community sooner or later. ♦

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Thank you again for your editorial and for your letter.

EXCEPTIONAL PARENT®

Parenting your child with a disability

Volume 18, Number 7 October 1988 $3.50

Bush & Dukakis SPEAK OUT

SIXTH ANNUAL TECHNOLOGY ISSUE

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EDITORS' DESK

Here is our Sixth Annual Technology issue complete with an up-to-date resource directory. The contributions of technology no longer seem as unbelievable as they did six years ago. Technology is changing the present and the future as well as our viewpoints from the past about active community participation by children and adults with disabilities and their families. We congratulate Apple Computer, Inc. and IBM as well as the other high-tech companies who have committed resources to the needs of people.

PRESIDENTIAL CANDIDATES

This is the fifth time that we are publishing statements of the Presidential candidates. In 1972, when we first published statements by the major candidates for President, most candidates for public office were unprepared to address issues of concern to parents, professionals and people with disabilities. And only a few courageous parents, professionals and people with disabilities believed that they had a right to approach candidates. While this has changed, there is still much to be done.

The excitement and fireworks of Presidential politics often overshadows the local political campaigns of candidates who can play critical roles in the day-to-day lives of children and families. However, it is these local candidates who, when elected, actually make the day-to-day decisions about the allocation of local educational, recreational and other resources. Each election year, we have an opportunity to educate and reeducate our friends and neighbors who are candidates. We also have the opportunity to help those candidates who support the specific needs of our children. In that way, each of us can really make a difference in the lives of children and families -- including our own.

RESPITE CARE SURVEY

Every regular subscriber has received a respite care survey questionnaire with this issue. We are pleased to be collaborating with the Human Services Group (Cambridge, Mass.) to identify respite care needs of families and then propose strategies to meet them at the local level. We need your participation. By completing and returning the questionnaire in the postage paid reply envelope, each reader can have personal input in this important project. We look forward to reporting the findings of the survey in the spring. Please return the survey as soon as possible. Thank you.

NEW BOOK

After school programs for children can provide respite for parents. We are pleased that Exceptional Parent Press' new book, *School-Age Children with Special Needs: What do they do when they're not in school?* by Dale Fink, is now available.

EXCEPTIONAL PARENT®

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Editor: Stanley D. Klein, Ph.D., Professor of Psychology, New England College of Optometry
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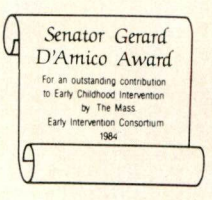

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Parenting your child with a disability

Volume 18, Number 7 October 1988

6TH ANNUAL TECHNOLOGY ISSUE

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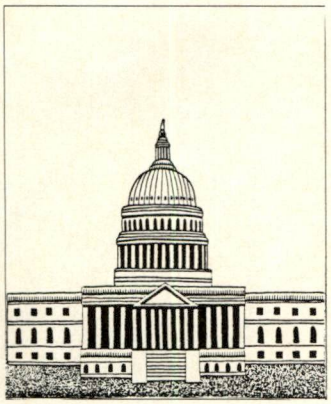

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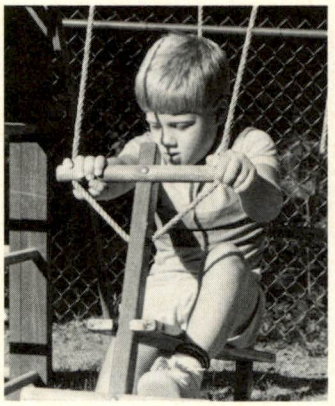

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Photo by Cheryl Cullen

LETTERS TO THE EDITORS

We welcome all contributions to Letters to the Editors. Please send your questions, ideas and responses to: EXCEPTIONAL PARENT, P.O. Box 657, Kenmore Station, Boston, Mass. 02215.

ZEPPY, DARWIN AND CALEB

When I finished reading "Darwin and Caleb" as well as "Insights from Zeppy, a Father's Essay" in the July/August issue I was struck by the common theme that people with special needs have in their own way "special qualities."

It is indeed a question of setting our values straight as Sal Biondello points out in "Insights from Zeppy." And I was touched by Susanne Carter's presentation of her two children and her sense of appreciation of the level of development for each of them.

These two articles reminded me of a favorite story I often repeat when I address parents of children with special needs that I call "Lassie and her own special values."

Like Susanne Carter, my first child, Lisa, was born with Down syndrome. Two years later along came Paul; I too had to work on the communication gap and create positive thinking about having a person who is mentally retarded in the family.

I knew that it was important to show to Paul what Susanne Carter stated so well: "not all normal patterns of behavior are necessarily positive and not all abnormal behavior are necessarily negative." So at every occasion I tried to pick out the positive qualities for Paul to see in Lisa. When Paul was at the age where he was collecting baseball cards that he got when purchasing bubble gum, he would often say to Lisa, with an endearing smile on his face, "Lisa, you want bubble gum, don't you?" In her eagerness to please she always agreed, whereupon he inveigled her to give him her share of the baseball cards. I would wryly say to him, "See, sometimes it is OK to have a sister you can manipulate."

However, I did succeed in showing Paul that Lisa indeed had her own special values. I owe this to the television show *Lassie* with that wonderful dog. One night Paul, Lisa and I were watching when the little boy asked his mother, "Can Lassie catch beavers?" His mother responded "no," and the little boy looked crestfallen. But then the mother quickly responded, "But Lassie can do many other things -- she has her own special values." I quickly picked up on that and said to Paul, "You see, you have asked me several times why Lisa talks funny, but Lisa, like Lassie, has her own special values."

I wasn't sure Paul fully understood this. He was only five years old at that time. But that summer when we went away to a family camp in the country, I overheard a little boy say to Paul "your sister talks funny." Then he stamped his little foot and responded proudly, "So what, she is like Lassie; she has her own special values."

This phrase has helped all of us along the road. When Lisa used to come home from school and sadly tell me that someone on the street made fun of her, I would retort promptly, "Don't feel badly -- he doesn't know that you have your own special values."

Indeed, I found this philosophy helped me tremendously in dealing with the sibling situation, in dealing with giving Lisa a good image of herself, and in dealing with redefining my own values just as Sal Biondello points out.

I am pleased to report that this attitude has had a positive result because Lisa, now age 33 and living in a group home, quite independently, tells everyone how terrific she is doing her own thing. At the same time, Paul, now a doctoral student in psychology, delights in educating his friends with Lisa's many accomplishments. And I enjoy the special values that each of them give to me.

Betty Pendler
New York, New York

AUNT DOROTHY AND MEREDITH

What a lift I got from reading the article "Aunt Dorothy and Meredith" in your July/August issue. While my son doesn't have an apparent genetic basis to his mental retardation, and we will probably never know the cause, I have often wished I could somehow find out more about our family background to see whether anyone back in our family ever had something similar. But with hardly any family around, this isn't possible for us.

How wonderful, then, for the Shears to have had the opportunity to meet Aunt Dorothy and listen to her story of her little brother, to feel that extra link to the past and yet derive some comfort in hearing first-hand just how times have changed for the better for children with disabilities.

And, as I looked at the family picture, it appeared to me that the delightful little girl on whom the article was based just might be the same Meredith who was on my son's special tee-ball league team two years ago!

Geralyn Jacobs
Commack, New York

CLOTHING ALTERATIONS

I am writing to share a clothing alteration idea with fellow readers.

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found selecting appropriate clothing to sometimes be a challenge. Winter coats were a particular problem. My daughter is confined to a wheelchair and needs several support systems (lateral supports, seat belt, front yoke harness, knee abductor, and foot rest straps) to maintain positioning.

Removing these, standing her to put on a coat, repositioning her in the wheelchair and readjusting all the straps and supports every time we went "out" was very time consuming and tiring for both of us. And of course, this process had to be done in reverse every time we went "in" so she did not become overheated. You can imagine what a day with several appointments was like -- an all around nuisance.

So I came up with an idea for an alteration that has worked wonderfully. I removed the back of her coat. This allows for the coat to be slipped on from the front over all her supports without her having to move. It can be tucked in along the sides and around her legs, while her back is kept warm against the vinyl of the wheelchair. And it looks like a perfectly normal coat.

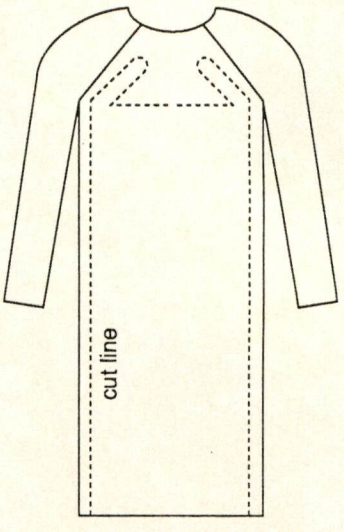
As for the actual mechanics of this, it is very simple. Depending on the type of support system, you probably need a coat somewhat larger than the child's normal size. I have found a coat with raglan sleeves works best.

Somewhere near the side seam -- depending on how much fabric you want to wrap around the body -- I cut up the length of the coat on both sides continuing up the sleeve seam to about two inches from the neckline. I then leave a triangular-shaped piece along the neckline that is used to tuck behind her back.

I have expanded this idea to all her coats and jackets, including a rain slicker.

I am writing this letter because so many people have encouraged me to find some way to share this information with other parents. Since I have enjoyed being a subscriber for nearly all of my daughter's 15 years, I felt your magazine may be an avenue to accomplish this.

Ruth A. Settle
Library, Pa.



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PARENTS SEARCH

EXCEPTIONAL PARENT will publish letters from readers searching for parents with similar experiences, information about specific problems, and other resource information. Subscribers may publish one letter a year in Parents Search without cost. Anyone who wishes to reply to a letter in Parents Search should write to: EXCEPTIONAL PARENT, P.O. Box 657, Kenmore Station, Boston, Mass. 02215. Please indicate in which issue the letter was printed when addressing your reply. All replies will be forwarded and may be published in our Parents Respond column.

PORTABLE OXYGEN SYSTEMS

We have a five-year-old son who was a 25-week preemie and has bronchopulmonary dysplasia (BPD) as his major problem. He is still on oxygen all the time and has become very mobile in the last year. We would love to "network" with other families who have older children with similar problems and are on oxygen.

The portable oxygen systems that we have found available are not the best we feel should be available. We would like to find a small, lightweight, well-functioning portable unit for our son. Please write if you have any suggestions. He is presently on a 50-foot tubing, which can be rather cumbersome.

S. D. & L..D.
Holden, Mass.

GROUP HOME PLACEMENT

My husband and I just placed our son Jimmy in a group home. This was the most difficult, painful and heartbreaking decision we have had to make, and we desperately need to hear from other parents who have had to make this decision.

We love Jimmy so very much, but things were becoming so tense in our home that it was no longer in Jimmy's best interest to keep him there. Jimmy is eight years old and is one of those children with varying "labels."

We have been told by the professionals that he is developmentally delayed, educably mentally retarded and autistic-like. We have been told that he has a neurodevelopmental disorder, a pervasive developmental disorder and an attention deficit disorder. No matter what label, Jimmy just became a tyrant in our home (that was partly our fault). He needed a break from us, and we from him. So the choice was made to place him in what we hope and pray will be the loving group home it appears to be.

Tadd and his friend Seth enjoy spending time together in the school library.

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We were also forced to make this decision because of the lack of support from family, friends, neighbors and professionals. Not one child in our neighborhood has ever made an attempt to befriend Jimmy. His Saturday special recreation program was discontinued by the county. We are living in a school district that thinks nothing of moving disabled children from school to school each year, thereby preventing them from making long-standing friendships.

So much has been left unsaid in this letter. We feel defeated. We feel helpless. We feel angry. We feel bitter. We feel guilty. We feel alone, so very alone. Are we?

C. C. & S. C.
Concord, Calif.

PARTIAL TRISOMY 10

Our daughter Rivka, who is two years old, was born with a virtually unknown genetic disorder named Partial Trisomy 10. From what we understand from our doctor, she has an extra "piece" stuck onto chromosome number ten. The various researchers have not been able to discover what the "piece" is. No one can tell us what to expect in the future.

While still in the hospital, feeding problems arose. She was tube fed for two weeks until we managed to feed her orally. Until the age of 14 months she was undereating and underweight. Along with the feeding problems, Rivka was very hypotonic (she still is, but less so). She started physical therapy at the age of five months.

After long debates, we agreed with the doctors that a feeding tube was the only solution. My husband and I learned how to insert the tube through her nose. From 14 to 20 months, she ate almost solely from a tube. The nutrition definitely helped. Her gross motor and fine motor skills developed quickly, as did her general interest in her surroundings. Since the age of 20 months we have been trying to eliminate the feeding tube, but it is still necessary to give her one meal with it (in the evening) in order to supplement her intake.

Today, at the age of two years, her verbal skills are non-existent, but she does understand simple sentences having to do with everyday life. She will be receiving speech therapy soon.

We would be very interested in hearing if anyone who has any information about this disorder, or any disorder with similar sounding symptoms, and what kind of treatment or programs are being used.

We would also be interested in hearing from anyone who has experience in eliminating a feeding tube that was in use for a long time. Thank you for your help.

H.L.
Jerusalem, Israel

LOOKING FOR SOFTWARE

I am hoping that someone can help me locate software for my 16-year-old, learning disabled son who must pass regents competency tests to obtain his high school diploma.

Software, such as Math Blaster, is wonderful but not for my son, because it doesn't explain how to reach the correct answer.

I have been in touch with Link Resources, but their database lists software prohibitive in cost.

In line with the above, we can no longer deduct the cost of software or other materials to help our disabled children, unless there are also unfortunate high medical expenses. Perhaps we can all write to our legislators asking for a special amendment to the tax reform bill for our special needs children.

The media is filled with items about the national disgrace of our schools. If the mainstream can't succeed, how can our children?

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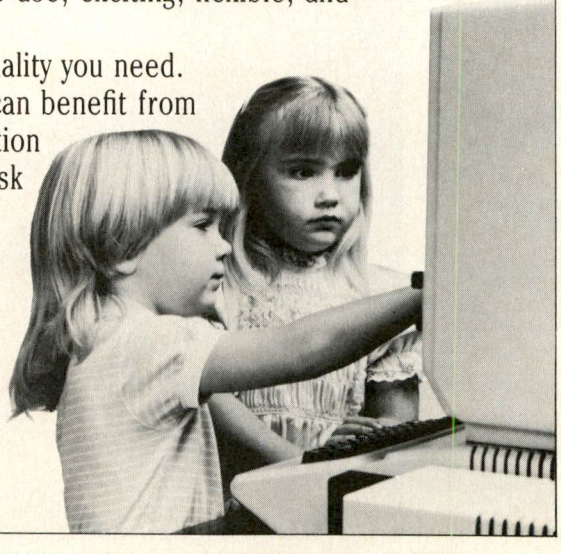

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Of course, the parents of gifted children will want the same for their children, but gifted children manage to do well in spite of the educational systems.

R.A.
Brooklyn, N.Y.

RURAL COMMUNITY

We are the parents of a 23-year-old man, who has a seizure disorder and a developmental disability. He wishes to start a rural community for teens and young adults.

We would like to hear from parents with an interest in such an effort.

L.W.
Brooklyn, N.Y.

POLAND SYNDROME

My six-month-old grandson was born with Poland syndrome. His disabilities are a smaller right hand, webbed fingers, a shorter arm and absence of the pectoralis major muscle of the chest.

This is evidently a rather rare condition, and we are not aware of the cause. There seems to be a difference of opinion as to whether it is genetic or not.

I am interested in contacting other parents and grandparents who share this same problem. We are told nothing can be done except surgery for the sadactly of the fingers.

If someone who has experienced Poland's syndrome could share ideas and suggestions as to what to expect long term, I would be very appreciative.

C.B.
Baltimore, Md.

ENZYME DEFICIENCY

Our son is eight and a half years old. He was born with a rare enzyme deficiency called propionic acidemia. He also has seizures.

We would like to hear from anyone who has a child with this illness.

C.S. & D.S.
Rochester, N.Y.

ABSENCE OF THE CORPUS COLLOSUM

We are the parents of a happy one-and-a-half-year-old boy who is mentally and physically disabled. A problem we face is that his symptoms do not fit into any known syndrome.

He has a congenital, structural, central-nervous system abnormality consisting of, among other things, absence of the corpus collosum. His development is markedly delayed, and he has microcephaly (small head), club feet, underdeveloped thumbs and radial bones and is diagnosed as being cortically blind.

He is very small for his age, below the third percentile, and is fed via a gastrostomy tube. Our son has had a tracheostomy in place since he was a month old because he has laryngomalacia.

Presently, he is on two medications: Phenobarb for a seizure disorder and Captopril for hypertension. He has been on many different medications over the past year and a half.

We really are in the dark as far as what to expect in the future for out son. If there are any parents who have children with one or more of the above conditions, we would appreciate hearing from you. Your information may shed some light on the problems of a very special child.

B. M. & B.M.
Forestburg, Alberta
Canada

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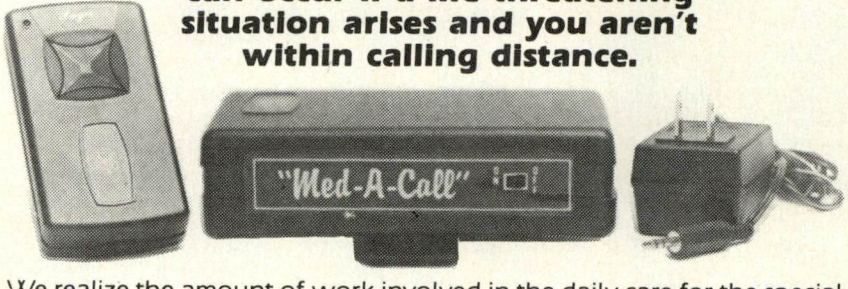

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PARENTS RESPOND

In response to L.N. and D.N. who requested information about infantile neuronal ceriod-lipofussinoses (Parents Search, July/August 1988).

Editor's Note: This condition is also refered to as Battens disease or Batten-Vogt syndrome.

You cannot imagine how surprised I was to see your letter in EXCEPTIONAL PARENT magazine. I have periodically considered writing just such a note.

In our case it is suspected our nine-year-old daughter, Christine, is in the juvenile stage of neuronal ceriod-lipofussinoses (CLF). We have had extensive blood work ups at the Institute for Basic Research (Staten Island, N.Y.), as well as a skin punch. Other blood work ups have been done at the hospital where our pediatric neurologist is associated.

Because her cellular involvement is still at a low level, her diagnosis is being reserved. Apparently, when 50 out of 110 red blood cells are involved, then a conclusive diagnosis will be issued. At this moment, she has only 20 blood cells showing the debris.

They also believe we inadvertently helped her by researching the condition and devising a sort of "meal plan" of our own. We immediately put her on 200 mg of vitamin E daily. We have since found out that in its juvenile form, there is a good response to vitamin E and selenium therapy.

Christine also has a seizure disorder and a mild form of cerebral palsy. Her learning disabilities stem from a combination of these conditions as well as some of the basic symptoms of CLF, such as a poor memory, inappropriate social behavior (i.e. too immature). Her basic skills are also poor -- abstract thinking, descriptive language -- in the low range. The best we can do is to maintain the skills she has and keep plugging along, keep her thinking, keep her doing

We look constantly for signs of regression or mental loss beyond the poor memory. We try to keep her physically active. We watch her daily food intake (cheating only when absolutely necessary) and we religiously give her her medications.

I cannot offer you any novel approach to what you must be facing. We're facing it too in our own way. Don't give up and don't give in to grief. The good days are great, and the bad days are desperate. No matter how hard I try to read up on it, investigate new information and *do* as much as I know how, I simply cannot adjust to it at all.

If you can, would you tell me about your daughter? I'm especially interested in how your neurologist suspected CLF and how he tested her. Has your neurologist mentioned anything about the studies conducted in Finland?

We've never met another parent whose child has this disease. It does help, in an odd way, to know someone out there knows what you are talking about and what you are going through. Our situations may not be identical, but we're in this together.

Kyrina McCormick
Pleasantville, N.Y.

We have a nine-and-a-half-year-old daughter suffering from the late infantile form as well. She was diagnosed five years ago. I have a lot of information on the disease, parent support groups, networks, parent-peer phone communication, research information, and most of all, personal experience raising a child with this disease.

I would love to be put in touch with this family and to help them in every way I can. This is a very devastating disease with no cure at the present time. Our best hope now is to come together as a family to support one another and share information. We are striving to reach all families. Currently, there is very prominent research taking place in Staten Island, N.Y. They are seeking all available information.

I would also like to express my appreciation to EXCEPTIONAL PARENT for quality information. Incidentally, I was personally introduced to the magazine by a friend who also has a child with Battens disease.

Linda Pierce
New Carlisle, Pa.

I cannot believe all the cases of infantile neuronal ceroid-lifofuscinoses, or Battens Disease, that are popping up.

I have a seven-year-old boy who was diagnosed as having Battens disease last year. Since he was eight months old we knew something was wrong, but nobody knew what. Up until last year, we were told he had cerebral palsy. Michael cannot sit, walk or talk. I do everything for him. I have two other children who are OK -- a girl, ten, and a boy who will be four.

I am curious to know what your neurologist told you to expect in the future. Everything I have read about Battens says the infantile stage has a life span of about five years. They tell me there are variations. Michael has a lot of orthopedic problems, including very bad scoliosis. He eats well and is pretty healthy.

Have you been in touch with the Battens Support Group? The woman in charge is Judy Grant, and their address is: Battens disease Support Association, 6707 1097th St. East, Spanaway, Wa. 98387, (206) 847-2926. I have been in contact with two mothers locally who have children with it. I have some literature on Battens, if you're interested.

The part I find the hardest is not knowing what to expect in the future and will I be able to care for Michael. Everytime he exhibits a different behavior, I think "is this part of Battens?" Sometimes I wish they never told me.

Michael goes to AHRC five days a week from nine to three; that helps alot. He is difficult to handle. My mom lives with us and that helps, but he's getting hard for her also.

I would love to hear from you and help in any way I can. If you would like, I'll send copies of the information I have on Battens.

Gail Canale
Franklin Square, N.Y.

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CAMA

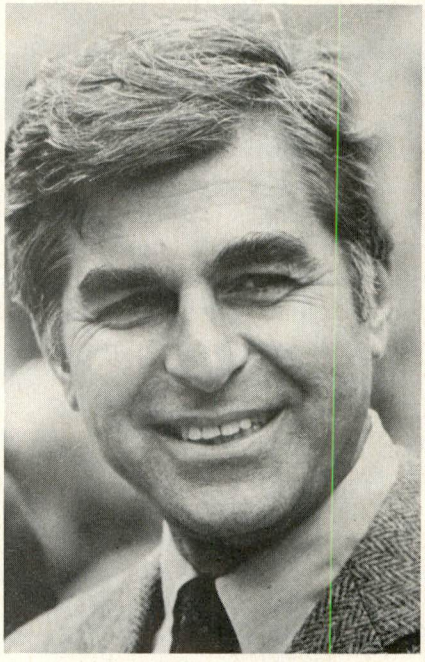
Michael S. Dukakis

Building a society that offers genuine opportunity to every citizen must be the top domestic priority for the next president of the United States. People with disabilities have the same needs and aspirations as all Americans: decent housing, a good job, a first-rate education, affordable health care, the opportunity to live with their families and to enjoy the community in which they live.

As a nation, we are all diminished by discrimination toward citizens with disabilities. My goal is to reassert the role of the federal government to promote integration, social and economic independence and equality of opportunity for all individuals with disabilities.

The next president must make it clear that discrimination against people with disabilities will not be tolerated. I supported the Civil Rights Restoration Act from the outset and as president, I will demand vigorous enforcement of Section 504 of the Rehabilitation Act of 1973 to prohibit discrimination by institutions that receive federal funding. I will also insist on strict enforcement of the Fair Housing Amendments Act of 1988.

The Americans with Disabilities Act of 1988 is a major step in ensuring that the civil rights of Americans with disabilities are fully protected. I support the principles of this legislation, which ensures full participation and equal opportunity for all citizens who have disabilities.



"My goal is to reassert the role of the federal government to promote integration, social and economic independence and equality of opportunity for all individuals with disabilities."

For children who have disabilities, educational opportunity is society's most productive investment. However, the attitude of the present administration toward funding of special education has been penny wise and pound foolish.

I support more effective federal cooperation with the states to implement the Education For All Handicapped Children Act (P.L. 94-142). We must ensure that children with disabilities are educated with their non-disabled peers to the maximum extent appropriate. But our commitment must not end with classroom instruction. In Massachusetts, we have implemented the landmark "Turning 22" law to develop a transitional service plan for each student leaving special education and needing continuing support to live and/or work independently. The federal government can provide leadership that encourages other state and local governments to provide similar services.

We know that early intervention for infants and toddlers significantly decreases the need for special education and other services later on. This results in both cost savings and improved functioning for these children and their families.

I believe the federal government must provide leadership in working with states to promote cooperation among federal agencies serving young children with special needs and to develop guidelines to assist states to set up effective early intervention programs.

When Americans with disabilities who want to work are excluded form employment, the entire nation bears the cost. I will work to restructure benefit programs to provide reasonable incentives and appropriate support for people with disabilities. My administration will set a goal of ensuring that every adult who has a disability has the opportunity for a good job at a good wage.

Under the Reagan Administration, federal support for barrier-free, low-rent housing has declined 70 percent, and the existing housing built with public funds has been allowed to deteriorate.

Housing opportunities for people who have disabilities will be thoroughly integrated in the National Partnership For Affordable Housing, a plan I have proposed that combines private investment with public initiative to make decent and affordable shelter the birthright of every American.

Access to affordable and adequate health care coverage is important for all Americans and especially for citizens with disabilities. Many people who have disabilities are unable to enter the work force for fear of losing essential health care. Others can work only by carrying a staggering burden of uninsured medical fees, equipment costs and personal assistance services. The best way to ensure fully adequate health coverage across the board is a national program of universal health care like the one I recently signed into law in Massachusetts. This program allows adults with disabilities who work full or part-time, as well as families with children who have disabilities, who are unable to obtain adequate employer-supported coverage, to buy a comprehensive state plan covering virtually all disability-related costs that are not covered by their employer's insurance plan.

Without adequate transportation, real equality of opportunity is impossible. The goal of federal policy must be the provision of equal access to affordable, accessible public transportation. I will see that every community moves toward the expansion of accessible transportation systems.

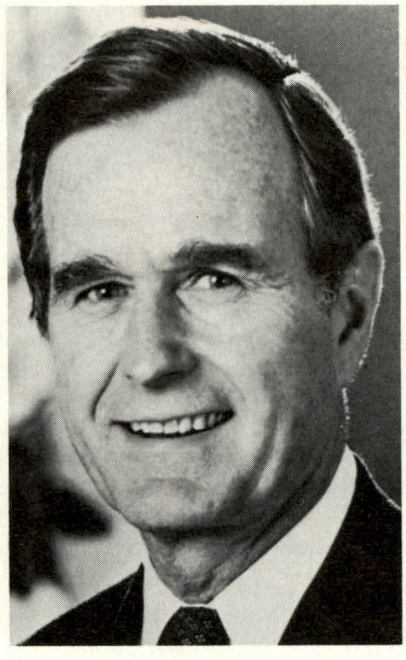
The independent living movement is at the heart of the effort to secure the civil rights of people with disabilities and to develop services that respond directly to their needs and aspirations.

We need to promote community and home-based health, rehabilitation and independent living services covered by public and private insurance programs, as well as other public and private resources. We must develop flexible, dignified

Dukakis continued p. 14

George H. Bush

The vast majority of the 36 million Americans with disabilities believe that their lives have improved in the past decade. Attitudes toward people with disabilities are changing in a positive direction and more people with disabilities than ever before are being educated. These are some of the findings of the first comprehensive survey of people with disabilities, conducted by Lou Harris and Associates and released in 1986. But I firmly believe, and the survey also indicated, that without aggressive public and private support, people with disabilities will not be able to achieve their highest priority, namely, the independence necessary to achieve control over their own lives and integration into the mainstream of American life.



By speaking with experts, with people with disabilities, and with parents of children with disabilities from around the country, I have learned much more about the needs of disabled individuals. I understand what people with disabilities strive for -- independence, control of their own lives, and integration into society. Many of the disabled I have met with have major responsibilities in local and national organizations such as The National Council on Independent Living, National Parent CHAIN, Capitol People First of Sacramento and the Assoc. on Handicapped Student Service Programs in Post-secondary Education, which are all run by and for people with disabilities. I am proud that from the start I have been able to speak directly with people with disabilities and the parents of children with disabilities, bypassing the intermediaries.

"We must develop programs and policies that promote independence freedom of choice and productive involvement in the social and economic mainstream."

These individuals made it very clear that those in the disability rights movement have two critical goals: the right of people with disabilities to control their own lives and make meaningful choices; and, the right to be integrated into all aspects of society. As far as education, the Republican Platform includes a commitment to protect the rights established under the Education for All Handicapped Children Act, which mandates a free, appropriate public education for all children with disabilities.

These goals may sound revolutionary in regard to the treatment of people with disabilities; but they are not radical in relation to the American values of individual freedom of choice and involvement in the social, political and economic mainstream. Although children and adults with disabilities have made many gains in the last decade, the stark fact remains that unnecessary segregation and exclusion of people with disabilities continues. As a result, disabled adults and families with disabled children suffer from stress, dependency and isolation.

We must remember that we are addressing a large and significant percentage of Americans. The Harris survey established that over 36 million Americans have disabilities; nine million of these Americans are under the age of 16. Forty percent of all adults with disabilities did not finish high school -- three times more than non-disabled individuals. In 1984, 50 percent of all adults with disabilities had household incomes of $15,000 or less. Among non-disabled persons, only 25 percent had household incomes in this wage bracket. With respect to employment, only one in four persons with disabilities works full time, another 10 percent work part time. There are at least eight million unemployed individuals with disabilities who want to work but need help finding employment. The statistics consistently demonstrate that people with disabilities are the poorest, least educated and the largest minority in America.

We must develop programs and policies that promote independence, freedom of choice and productive involvement in the social and economic mainstream. This does not merely mean employment. It also means access to the mainstream educational system, to public accommodations, to public transportation -- in other words, meaningful access to all aspects of society. Further, we must include people with disabilities and their parents in the process to ensure that their real needs are addressed.

The stakes are enormous. On the cost side, the National Council on the Handicapped states that current spending on disability benefits and programs exceeds $60 billion annually. Excluding the millions of disabled who want to work from the employment ranks costs society literally billions of dollars annually in support payments and lost income tax revenues. On the benefit side, the United States is now beginning to face labor shortages as the baby boomers move through the work force. People with disabilities offer a pool of talented workers whom we simply cannot afford to ignore, especially in connection with the high tech growth industries of the future.

During the past six years, I have advocated the appointment of persons with disabilities and parents of persons with disabilities to major posts in the federal government. As president, I will expand the number of persons with disabilities and parents of persons with disabilities appointed to key positions in my administration.

Moreover, I pledge that my administration will do away with "Hire the Handicapped Week" and replace it with federal legislation that gives people with disabilities the same protection in private employment that is now enjoyed by women and minorities.

Bush continued p. 14

MICHAEL S. DUKAKIS

personal assistance services to support personal independence, sustain the integrity of families and open avenues of employment. We can identify new and effective ways to reach out to persons with the most severe disabilities so that they too can enjoy the participation.

I have further supported the principle of self-determination of people with disabilities to leadership positions in key state agencies. I will continue to support the development of a strong national network of independent living centers. I will actively recruit people who have disabilities into all levels of government and public policy making.

For children with disabilities, their families are the major source of financial and emotional support. Families need and deserve far more assistance -- respite care, parent training and help in accessing and coordinating services.

People in need should be able to count on the federal aid to which they are entitled. The current administration tried to throw hundreds of thousands of people with disabilities off the Social Security rolls without due process. In Massachusetts, I ordered a moratorium on these cuts and created a process that became the model for national legislation to prevent recurrence of this grave injustice.

Together, we can build a new future for American citizens with disabilities: a future of dignity, security and equal opportunity -- a future that will demonstrate that citizens with disabilities are full partners in society and equal partners in building a foundation of equality for all. ♦

GEORGE H. BUSH

In order to assume that every American who wants a productive job in the private sector has a job, I will continue to support initiatives to:

- Ask the private sector to work more aggressively in hiring people with disabilities, using my office to educate employers about the statistics showing clearly that, other things being equal, disabled employees perform above average.
- Train people with disabilities for jobs that really exist where they live.
- Work with Congress to eliminate disincentives that discourage disabled persons who wish to work from working.
- Improve transportation and work place accessibility for existing facilities and insist on accessibility for all new construction.
- Support independent-living centers to help disabled persons with the transition to independence.
- Urge private insurers to find ways to include, not exclude workers with disabilities in their programs.

Individuals with disabilities are not a small, uniform minority with narrow interests. The disabled community includes every race, culture, age, sex and economic class. Membership is open to all and most of us who live our full life span will join this community sooner or later. ♦

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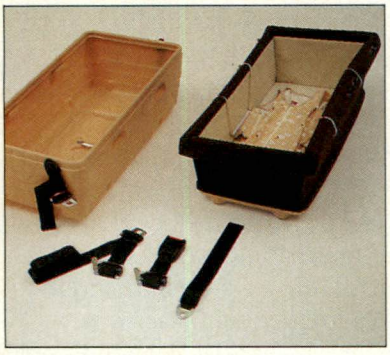

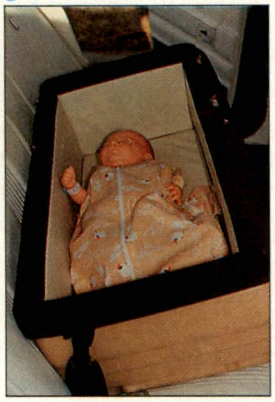

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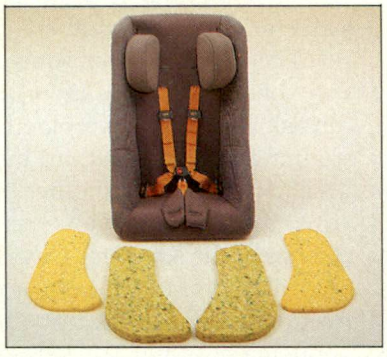

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A Song For David

Creating ways to communicate with a child who is nonverbal.

By Charlotte Forbes

David will do anything for a song. Sing him a song, and he is happy. If he could talk, I imagine he would sing all day. But because he is head-injured and therefore unable to speak, he has to settle for a song from others.

David has devised some rather creative ways of asking for his favorite songs. He can ask for one by stamping his foot, or spinning in a circle, a third by jumping with his back to you and another by waving his arms. These simple movements express the essence of the songs for David. For example, spinning in a circle is what "Ring Around the Rosie" is all about for him. Bouncing in someone's lap is the best part of another song. These movements communicate what he wants to say and show us what particular songs mean to him.

In order to help David develop communication skills, we have tried to understand what David wants most and what it means to him -- for example, the essence or most enjoyable aspect of the song. Because he is nonverbal, we have focused our efforts on alternative means of communication such as sign language, gestures, and communication boards. In using three different methods simultaneously, we hope to give him every opportunity to communicate and determine the most appropriate method for him to use.

SIGN LANGUAGE

David's use of sign language is an example of how we encouraged him to express the essence of his experience in a physical movement. For example, he loves to hold his hand near an open window in the car and feel the wind rush by. One day when he was fussing in the car, I asked him what he wanted. He held up his hand to the closed window -- a sign was born. Now whenever he wants to feel wind from a window, the blowdryer, or a hand dryer in a public rest room, he holds up his hand.

David's greatest love is music. Therefore, many of his signs are requests for specific songs. What he likes most about "Ring Around the Rosie" is spinning around in a circle. Since he is capable of spinning endlessly without a song, we decided to make his spinning into something useful -- a sign for "Ring Around the Rosie." Whenever he started spinning, we would interpret it as a request to do the song with him. Eventually, he

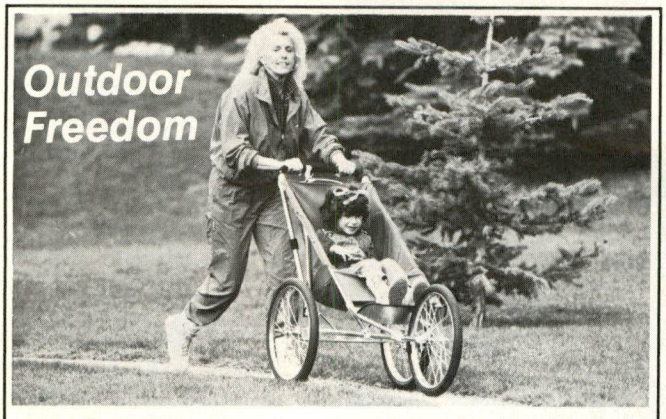
Photo by Cheryl Cullen

Standard sign language is preferable to David's made-up signs, but it would have been a lot more difficult for him to learn.

learned that spinning signalled to us that he wanted us to sing and play "Ring Around the Rosie."

David's favorite part of the song "This is the Way the Ladies Ride" is bouncing up and down on his father's lap. Since that is also the way to begin the song, David quickly learned to use it as a sign. As with most of his signs, at first he needed to understand what the sign meant and be taught to use it. We began by bouncing him up and down as he would to jump into his father's lap. Then we interpreted the bouncing as a request for the song. Once he learned the sign, we would not sing the song until he signed for it.

David was able to learn these three signs very easily and quickly because he wanted to be able to communicate them, and because the sign was so closely related to the activity itself. Certainly standard sign language is preferable to David's made-up signs, but it would have been a lot more difficult for him to learn. Our primary goal was to enable David to communicate. I feel that learning primitive signs in the beginning helped him to learn the standard signs he is now being taught.



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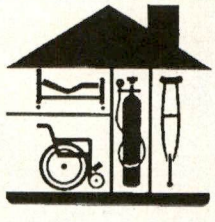

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GESTURES

We have also encouraged David to communicate through the use of gestures. His gestures are similar to his signs, although they are more direct and less specific in meaning. One of the first things I taught him was to lead me by the hand to what he wanted or needed help with. I began with the front door, because he loves to open and close it. When he stood at the locked door fussing, I would pull him to me and walk to the door with him hand-in-hand and unlock it. After many trials, he was able to take my hand and lead me to the door. Eventually, he learned to find me and lead me to the door, as well as other things he wanted.

When David goes to certain locations in the house, he is telling us he wants something. He sits on the couch where we always read to him when he wants us to read him a story. He sits in his seat at the kitchen table when he is hungry. We taught him to go to the refrigerator and open the door when he was thirsty He has since learned to carry the juice to the table and get his cup, but the process began with David opening the refrigerator door to say that he was thirsty. All of these gestures represent things that are very important to him.

David communicates the heart of an experience with his gestures. For example, he loves to eat. He identifies eating with being seated in a specific place at the table. One of the things he likes most about being read to is sitting on the couch with someone beside him. He was able to learn these gestures because they were so directly related to the experiences. Today David has a more sophisticated means of expressing these same things to us -- he uses standard signs.

COMMUNICATION BOARDS

To develop a communication board for David, we strove to apply the same principles we used when teaching him to sign and gesture. Once again we identified the most important and pleasurable activities, as well the essence of the experiences for him. Initially, an actual board with a choice of items (especially pictures of items) seemed too difficult, so we began with a single, loose object. We tried to think of an object that expresses what riding on a swing is all about, because David loves to swing. It was hard to find an object that would represent the feeling of flying through the air, so we settled for second best -- a braided rope similar to the ropes he holds on the swings. We left the rope by the swing, guided him hand-over-hand through picking it up and handing it to us. As he handed it to us, we told him that we understood he wanted to swing and gave him a push on the swing. After many trials, he gradually came to understand that giving us that rope communicated that he wanted to swing.

Photo by Cheryl Cullen

David and his mother playing with a bat and ball.

We introduced two more activities: drinking juice and playing with an adult. The cup David most often drank from signified that he wanted to drink some juice. To tell us that he wanted to play, we chose one of his small toys. Both were attached with Velcro to the wall. We taught him to hand one of the objects to us. If he chose the cup, we filled it with juice; if he chose the toy, we played first with that toy and then, keeping it right in front of us, we played with other toys.

We began using a board that contained objects that directly represented several of his favorite activities. We found that attaching objects with "tie-wrap" to a peg board was the most convenient method. We used a very small ball to indicate playing ball, a small book for reading, and a baby spoon for eating. We moved his hand from object to object identifying it as he touched it. He soon learned to touch each object by himself, and we told him what it represented. He indicated his choice by leaving his hand on the object, tapping, or vocalizing excitedly as we identified it.

We also developed a food choice board to enable him to make decisions about his meals and snacks. We started by letting David make choices between the foods put in front of him. Next we made a board with two foods, cheese and crackers, attached to it. This was slightly more difficult because he could not take the food from the board to communicate a choice to us. We slowly increased the number of choices and began to use objects that were symbolic of the foods rather than the actual foods. For instance, we used the lid of a yogurt container for yogurt, a small bell shaped like a piece of candy for candy, and a small plastic spoon for a spoonful of peanut butter.

In developing David's communication boards, we used objects that most directly represented a preferred activity and slowly moved to more symbolic ones. A

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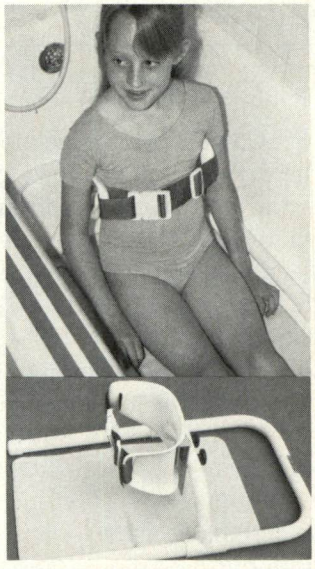

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book and a ball directly state a desire to read or play ball. We tried to find objects that were both representative and expressive of the activity. He drank his juice from the same cup he chose to indicate that he wanted juice. The rope reminded him of the ropes he held on the swing. He gradually moved to objects on his communication board that were symbolic of activities.

DAVID'S PROGRESS

David's communication skills have progressed since the days of cups attached to the wall and a rope by the swing set. He uses a communication book that contains photographs to indicate his choices. He has a decent-sized repertoire of signs, and several words. I remember thinking, "Why should I wait until he picks up the rope before pushing him on the swing?" or "Why are we even thinking of sign language -- after two months he still can't touch his hand to his mouth to sign for juice?"

But we kept at it, and in the process David made a wonderful discovery. David discovered that he could be a communicator. He could change something, request something or make a choice. By helping him to find a primitive means of expression, we showed him the joy of communicating. Once he knew the rewards of being able to communicate, he became extremely motivated. Learning new signs and gestures gave him power.

It was often difficult for us to help David develop communications skills -- to reach down to his low level of functioning and see things from his perspective. Yet it was crucial for us to identify these simple, basic, first steps because they were David's foundation. David saw that he could communicate by touching a piece of cheese or handing us a piece of rope and that communication had great rewards. We were able to find out what David was capable of learning by asking ourselves these few questions:

- What is important to him?
- If he could ask, what would he ask for?
- What does he enjoy about it?
- What is the experience like for him?

The answers to these questions left us with a little boy jumping up and down to ask us for a silly song, but they also left us with a little boy learning to communicate. Now, though we are often reminded of his limitations, we can also remember how far he has come. David can have his song. ♦

Charlotte Forbes received her master's degree in special education from Eastern Michigan University. She is a part time teacher at Dean Junior College in Franklin, Mass., and is a board member of the Blind Children's Fund. Charlotte and her husband, Harry, live in Wrentham, Mass., with their three children, David, seven, Gil, five, and Peter, two.

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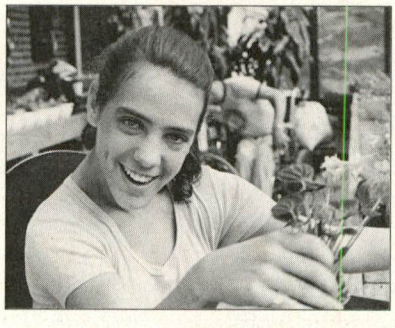
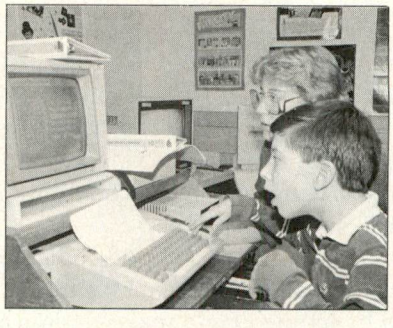

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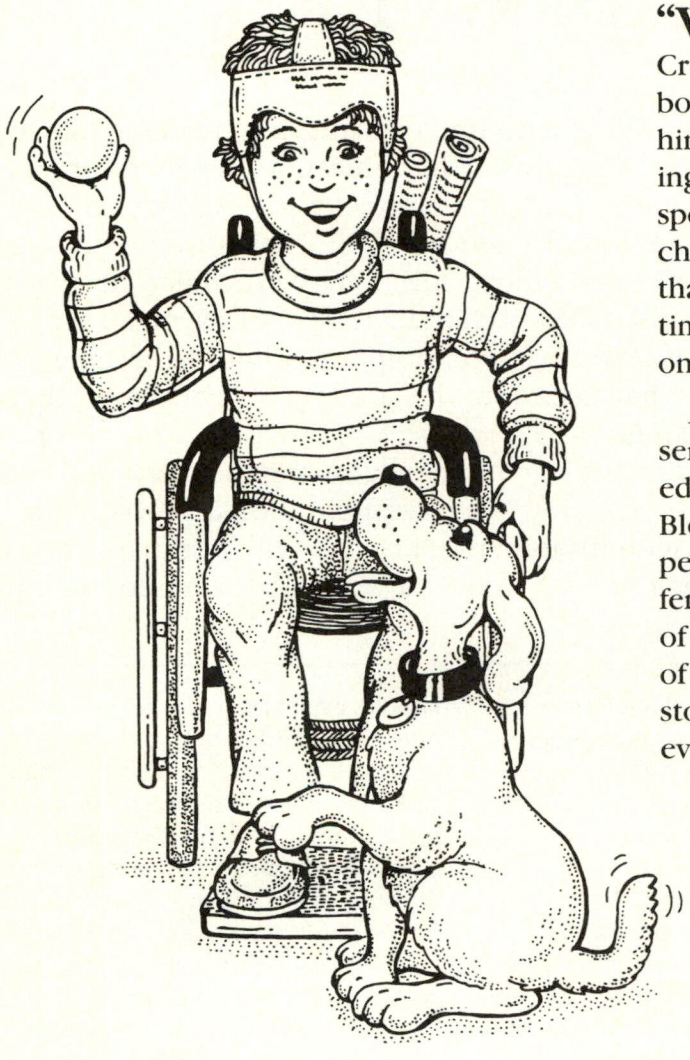

"World famous sports editor and champion Cruiser driver"—that's Mark Riley. Mark was born with cerebral palsy. That hasn't slowed him down though. Especially when he's wheeling in his "souped-up, super-sport, faster-than-a-speeding-bullet Cruiser"—you know, his wheelchair. In *It's Your Turn at Bat*, Mark discovers that strength must come from within when it's time for a big league play. It's "Batter up" for the one and only Mark Riley!

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ELECTRONIC COMMUNICATION AIDS:

QUESTIONS and ANSWERS

Understanding electronic communication aids will help you make the right choice.

By
Iris Fishman

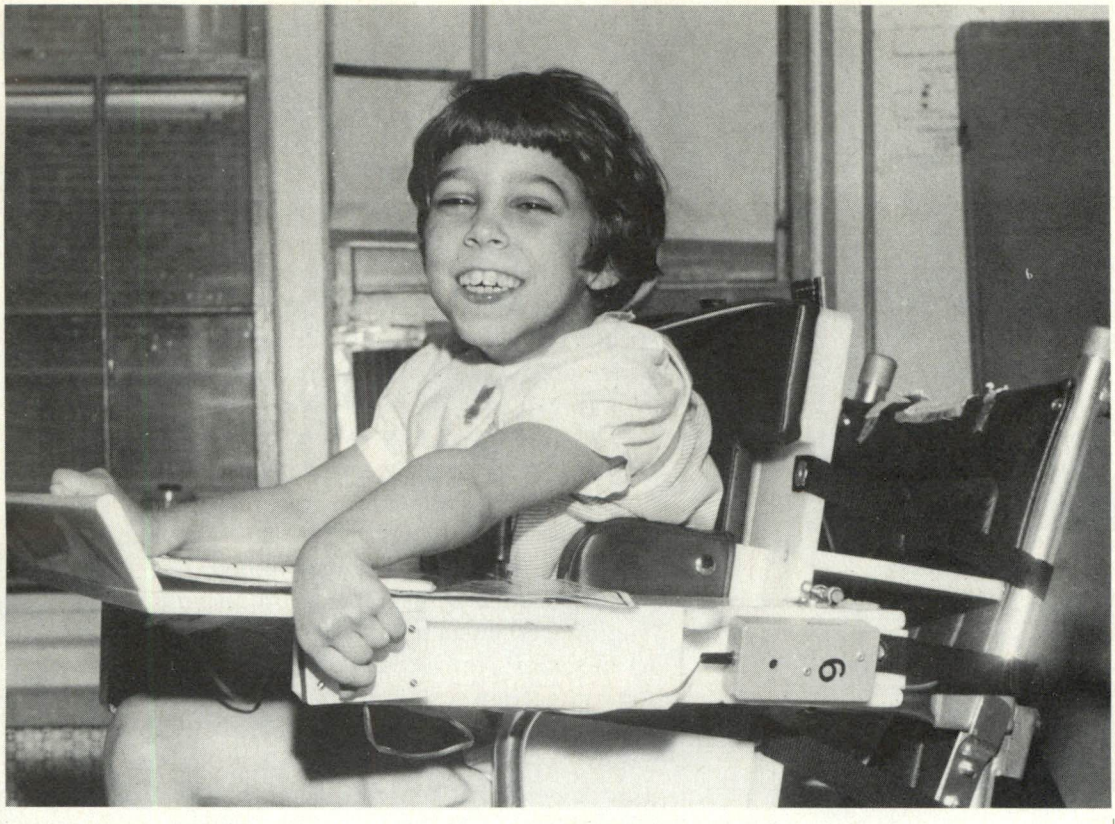
For children with severe speech impairments, technology offers more options than ever before. Electronic communication aids no have speech that is more natural sounding, larger memories allowing thousands of messages to be stored and rapidly produced, the ability to provide access to computers, and greater portability. Technology is developing at such a rapid pace that we are also faced with numerous options, making it essential that parents of severely speech-impaired children become knowledgeable about what electronic aids are available and what they can really do for their children.

Becoming knowledgeable is more than knowing the name of the latest speech synthesizer or subscribing to every publication involved with technology for people with disabilities. It begins with a realistic view of the potential of electronic aids and doing away with the misconceptions that often surround them.

Q ***My child speaks even though it is difficult for those who do not know him to understand him. If I get him an electronic aid with speech output, I am afraid he will stop talking altogether.***

Clinical experience has shown that if your child has a desire to communicate, he will not choose to use an electronic aid over speech; it is far too slow and inefficient. Rather than becoming dependent on the aid, a common occurrence is for your child to first attempt to use whatever speech abilities he has and then to persist in using speech, even when it is not understood after several attempts.

With proper training, your child will be taught to use his speech first and, if it is not understood, to use the electronic aid as a backup. By providing another approach to communication, the pressure is removed for the child, who relaxes and is better able to communicate through whatever speech abilities he has. As a result, his speech may become more fluent and intelligible. Using a communication aid your child can also indicate to the listener the topic he wants to discuss. This can assist the listener in understanding the child's speech.



Jennifer Johnston.
Story page 24

Q ***Once I get this electronic aid for my child, he won't need to use his sign language or his old homemade communication board anymore.***

As a result of the technological revolution in augmentative communication, it is easy to understand why parents might think of electronic aids as better than other means of communication. After all, a machine that costs thousands of dollars and can speak should be better than a board made from paper and ink. In fact, selecting these aids is never really an either/or decision. A child using an electronic aid will still need to use other means of communication. Just as we use gesturing, pointing, facial expressions and even writing to supplement our speech, your child will also need to use multiple modes of communication.

In certain situations, other modes may be more effective than the electronic aid. For example, if your child is laying on a mat, he may not be able to operate his electronic aid, but he may be able to indicate messages on his board or to use sign language. A decision as to when to use each mode of communication available to him must be made for each child. This is essential in order to provide an effective overall communication system.

Q ***Why should I spend three to four thousand dollars on this electronic aid when for the same money I can get my child a computer that can do much more?***

Many parents make the mistake of falling into the "computer trap." This is the belief that it is more important for a speech impaired child to use a computer than it is to communicate and that computers are better than communication aids and will somehow compensate automatically for your child's communication problems. There is a general confusion between communicating and using a computer, as if the two were interchangeable.

In many cases, providing your child with access to a computer may open the way to pursuing academic and vocational goals. In fact, for persons with disabilities, the ability to use computers is rapidly becoming a prerequisite for obtaining an education or pursuing a career. The use of a computer, however, would not eliminate the need for an effective means of communication, but simply make providing it more important. After all, if your child is in school but he cannot communicate with others, what good is his education? Regardless of how well a child uses a computer, if speech is not functional, he will still need a communication aid.

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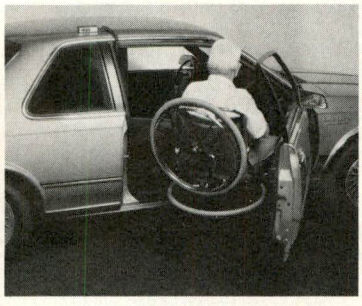

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Jennifer's Story:

Jennifer Johnston is an eleven-year-old girl with bright, shining, brown eyes, a winning smile and a quick sense of humor. She also has cerebral palsy and is unable to walk or, to speak. But with her electronic communication aid, which produces spoken and printed output, one soon forgets that she is disabled.

Jennifer did not always have this electronic aid. As a young child, she spent many years receiving traditional speech therapy in the hopes that she would develop intelligible speech. At the age of six, when it became clear that most of her communication was still being produced through laughing, crying, and answering yes/no questions, serious efforts toward developing an augmentative communication system for her began. This started with a simple communication board with three messages -- I want to go on the floor (because she liked to get out of her wheelchair to play with the other children); I want to go to the bathroom (because she was very concerned with letting those who took care of her know this); and Gina (because she loved to play with this particular classroom attendant). Jennifer was able to point to each of these messages with her left fist. Gradually, more and more messages were added to the board and, as they were added, her pointing skills became more accurate. Soon she had a board with over two hundred words and phrases.

Although her parents and teacher were delighted with the progress she had made, clearly the board was not enough. Jennifer needed an electronic aid that produced spoken output so she could communicate with other students, to people

Another result of the computer trap is that aids that are computer based (a computer that comes with software to make it act like a communication aid) are often considered better than those which are designed specifically to be communication aids, because consumers believe they can also perform other computer functions. It would appear that the purchaser is getting two devices -- one for computing and one for conversation -- for the price of one. With the increasing number of laptop computers now available, it becomes even more tempting to do this. In reality, however, most laptop computers that can run communication software cannot also run software appropriate to the educational needs of children.

Communicating her personality

standing across a room, or to those over the phone. Yet, she needed printed output because the ability to write would help her learn how to spell. Without spelling, she would always be dependent on someone else to program words for her into her electronic aid or write them on her communication board. She would never really be able to express her thoughts independently.

Last year, an electronic aid that would meet all her needs was selected. At first it seemed as if the aid would never replace her communication board. After all, she had been using the board for four years and it seemed to have everything on it she needed to say. But once the aid was on her lap tray and accessible to her all the time, she began to use it.

With her new voice, she discovered the power of telling a joke. She discovered singing. She also learned the power of writing and being able to do work independently without her mother or teacher. Because she now had a way to practice spelling, her spelling improved tremendously. Now if she did not have a word programmed into the device that she needed to say, she could often spell it. For example, when her parents asked her opinion about whether she wanted to enter a new school program, she spelled "Try it." As a result, there was less guessing about what Jennifer meant to say because she could be more specific about her thoughts.

Jennifer was always attractive, intelligent and funny, but in the short time she has had her electronic aid, it has enabled these qualities to be clearly revealed to all who meet her. In fact, the electronic aid has not only augmented Jennifer's communication but her entire personality.

Q ***There are so many electronic aids to choose from. It's impossible to come to a decision.***

Although there are many different electronic aids available, once your child's communication needs and physical abilities are established, selections can usually be narrowed down. This is because devices tend to be designed around the user having specific physical and cognitive abilities. For example, if a child is unable to walk or to use his hands or a headpointer for directly selecting items, is not yet able to spell, and needs printed and spoken outputs and computer access, there are really only about three types of commercially available aids that will meet his needs.

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The problem is usually one of gaining access to information, equipment and professional expertise and not in making the actual decision of which aid to purchase.

The greater problem you face is how to find out what the three choices are, how to see them demonstrated and how to give your child a trial period of use with these aids with the assistance of a professional who has an expertise with these devices. Some areas of the country are better serviced than others by electronic aid manufacturers or professionals specializing in augmentative communication. Thus, the problem is usually one of gaining access to information, equipment and professional expertise and not in making the actual decision of which aid to purchase.

Q ***Maybe I should wait to select an electronic aid until next year. By that time a better aid will be available.***

Everyone wants to know whether a better sounding, faster, more portable device is coming out soon. The answer is -- yes, there is -- but there always will be. Technology is rapidly changing and communication aids can be expected to be replaced with greater frequency than previously. Because of this, parents are often afraid to make a selection for fear that today's new model may be obsolete tomorrow.

It is only natural that you will want to take advantage of new developments as your child's system wears out and as new aids become available that meet his needs more effectively. This means that an aid selection is usually not final, because as your child's needs change, he will both need and want a new one.

What is important is to know is when to stop searching, reading, questioning, and when to make a selection. Since there will always be new and more effective developments, care must be taken that waiting for a better aid does not mean that your child is waiting forever. His communication needs need to be met now.

Q ***Once I get my child this electronic aid, all his (and my) communication problems will be solved.***

Getting your child the communication aid is only the first step. Training him to use the device in an effective manner for conversation and selecting messages to store in the aid that will help him adapt are also essential components.

Professionals now realize that storing groups of messages that relate to a particular situation is more effective than storing single requests.

For example, how many times have you seen a communication aid with messages like "I want to go to the bathroom," "I'd like a drink," and "I want to watch television" stored in them? If that were the only type of messages we could say, just think what conversation would be like! Someone would ask you how you are, and you'd only be able to respond with a request. More likely, you would forget about the aid and answer with a smile or some other means available to you.

Professionals now realize that storing groups of messages that relate to a particular situation is more effective than storing single requests. For example, if you child wanted a drink, he might say, "Gee, I'm really thirsty. A cold drink would be great right now." The person he is talking to might say, "How about some juice?" and the child would say, "OK." After a few sips, the child might then say, "I'd love some more," and then "That's enough for now. Thanks." Storing messages like these gives the child the opportunity to not only get his needs met but to interact with others in a more natural way.

Thus, finding a professional knowledgeable in the area of augmentative communication who can either train those working with your child or work directly with him is part of having an electronic communication aid that is successfully used and integrated with your child's other means of communication.

For information on professionals, agencies and regional support groups specializing in augmentative means of communication in your area, contact the International Society for Augmentative and Alternative Communication (ISAAC), P.O. Box 1762, Station R, Toronto, Ontario M4G 4A3, Canada. ♦

Iris Fishman received her master's degree in speech and language pathology from Hunter College in New York City. She is an augmentative communication consultant for United Cerebral Palsy in Bridgeport, Conn., and other agencies in the New York metropolitan area. Iris is the author of *Electronic Communication Aids: Selection and Use*, © 1987, a book for parents as well as professionals. It is available from College Hill Press, 4284 41st Street, San Diego, Calif. 92105, priced at $17.50.

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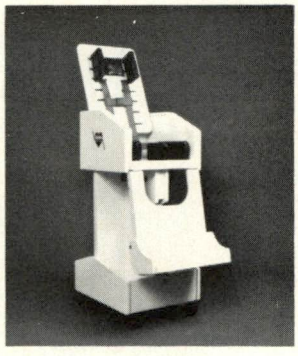

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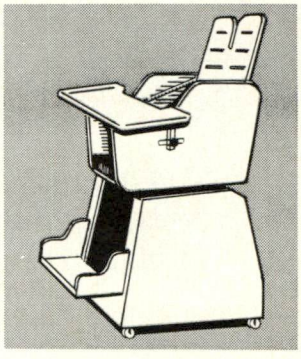

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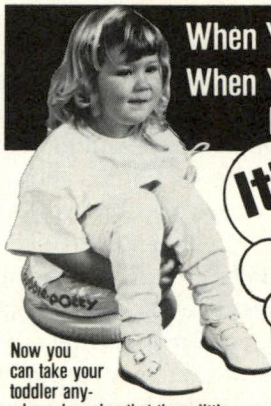

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Establishing an Assistive Device Lending Library

How to improve services in your local library.

By Douglas Haynes

Many parents are becoming more aware of the benefits that assistive devices and adapted switches can provide to enhance the quality of life for their children with severe disabilities. Assistive devices can be classified into nine categories: personal care aids; alarm devices; communication aids; environmental controls; mobility aids; recreation aids; educational aids; homemaking aids, and vocational aids. These devices can be used to give a child with disabilities greater independence and to allow the child to operate appliances and communicate in ways not possible without these devices.

The major difficulty in selecting the switches that work best for a child is having access to a wide variety of switches that the child can try. The best professional interdisciplinary assessments of what kinds of switches should be prescribed may not be correct. Trial and error is often the only way to select a switch that the child can easily use.

Parents who have tried to borrow devices from manufacturers on approval know the problems this strategy entails. First, there is the long wait before items become available for trial use. Most companies, if they permit free trial loans at all, will only allow the loan of one device at a time. If a number of different devices need to be tried, the time spent determining the best switch for the child can take a very long time indeed. Second, although some companies will rent switches for trial use, if many switches need to be tried, a large rental fee will be spent that could have been spent on purchasing suitable devices.

Your local school, public, or rehabilitation facility library can help in solving this problem by having a wide variety of switches on hand to test with your child. We established an assistive device loan program in the spring of 1988 at the New Mexico Developmental Disabilities Library, which serves severely disabled persons throughout the state, as well as providing informational services to rehabilitation professionals, families, and the general public in the state. This loan service has proven to be a valuable addition to our library services for persons with severe disabilities.

CHOOSING THE LIBRARY

Parents in most communities will first want to make their proposal to their local school or public libraries. Whether a parent should first approach the local school or public library depends on several factors.

If the child's school has strong administrative support for special education programs, has an active network of parents of students with disabilities, and has a good resource center for special education materials administered by the library, the school library is the place to start. Public school libraries can get access to the federal grant monies for educational materials for students with disabilities.

If, however, parents meet with a great deal of resistance to such a program at the local school, the public library would be the place to try. In this instance, the parent would want to coordinate with the local chapters or organizations interested in the welfare of persons with severe disabilities. A proposal to initiate an assistive device loan program will carry much more influence with the joint sponsorship of every civic group possible, as well as the support of your local political representatives. Also, if your community has an active Friends of the Library group, it would definitely be helpful to include them in the proposal process.

WRITING THE PROPOSAL

None of your "targeted" libraries will expect a master's thesis-level proposal, but they will expect solid information. The possibility of a favorable response to your proposal will be enhanced by footnoting and appending a selected bibliography. So, someone with university-level research and writing skills should be recruited for this purpose. If you have access to a university library with a current special education collection, or access to any good resource center on information dealing with severe disabilities, the task will be much easier. In fact, having access to this information is quite essential to writing a good proposal. It would even be worthwhile if one must travel some distance to obtain these resources.

Below is a descriptive outline of the organization of such a proposal proven to be successful.

I. Introduction

Define and describe what assistive devices and adapted switches are. Explain how they can be used by persons with disabilities in their education, habilitation, leisure, and daily living activities. The following is an example:

> Several kinds of nonprint media and materials are used to support educational, habilitational, and recreational programs for individuals with disabilities. These media and materials include audio visual hardware and software and regalia of all kinds, including toys, puppets, games, functional teaching aids, and specialized sensory stimulation materials.

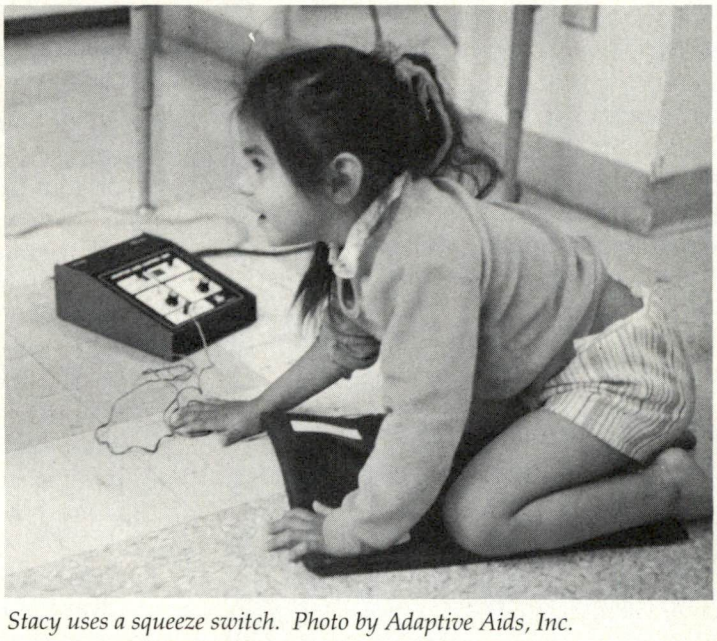
II. Statement of Need

Document the problem of assessment in fitting the right device to the right person by citing professional publications. Likewise, emphasize the fact that persons with severe disabilities are an under-served population by most libraries.

Obtain copies of the mission and goals statements from the library and its supervising departments. If it is the case that the library is not fully meeting its mission statement in terms of providing services to all people, particularly in alternative services to persons with special needs, explain this lack of service as clearly and logically as possible. An example is quoted below:

> A unique challenge in special librarianship is the provision of services to severely disabled persons who remain developmentally unable to read for their entire lives. These persons are generally severely or profoundly mentally retarded with multiple physical disabilities.

A proposal to initiate an assistive device loan program will carry much more influence with joint sponsorship.



Stacy uses a squeeze switch. Photo by Adaptive Aids, Inc.

FREESTYLE©

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The Freestyle Program is designed specifically for the physically challenged. With basic pointing skills, challenged students can respond to teacher instructions on their Freestyle Keyboard.

Important: Can be mounted on vertical, horizontal, or overhead surfaces; runs programs such as Lotus 123, Word Star, Symphony, etc.

The Freestyle Keyboard System is designed to be used with IBM PC, XT, AT, or compatible equipment.

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714-593-0490

A rural community for children with mental retardation and other handicaps

- Beautiful homes with permanent house-parent families, small groups, no shift workers, natural foods, live-in staff.
- Waldorf Education curriculum emphasizing creativity, with academic and practical skills for mind, heart, body.
- Curative approach toward individual needs. Wide variety of therapeutic treatments, resident doctor.
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- International affiliates, founded 1939, nationally recognized.

BEAVER RUN CHILDREN'S VILLAGE

FOR INFORMATION CONTACT:

Camphill Special Schools, Inc.
Glenmoore, PA 19343
(215) 469-9236

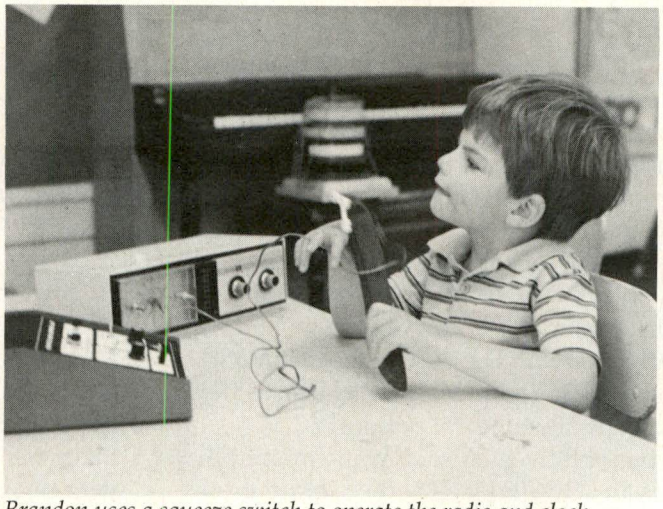


Photo: *Adaptive Aids, Inc.*

Brandon uses a squeeze switch to operate the radio and clock.

III. How the Library Can Meet This Need

Show how an assistive device loan program can specifically fulfill the library's mission statement by providing alternative services to people with disabilities. Examples of this improved access could be by: (1) allowing persons to determine which device will permit them to operate a reading light so they can be more independent in choosing their reading times; (2) allowing people with disabilities to operate audio visual equipment so they can more fully participate in the library's audio visual circulation programs; (3) giving persons who use wheelchairs more mobility in being able to visit the library, attend library functions, and browse through library collections.

Emphasize the fact that this loan program would only be to facilitate the choosing of the right switch for the right persons; so that the device could then be obtained by the person. List and describe similar library programs established elsewhere.

IV. Suggested Funding Sources

If your library is well-funded to the point that they can establish and maintain such a program with their present funding, this case will be the exception.

For any school, public, or rehabilitation facility library that qualifies for an Internal Revenue Service 501(c)(3) exemption, private foundation grants should be applied for to begin this program. Even exceptional parents organizations may qualify for these monies. If a library does not already have this exemption, inquiries should first be made to library administrators as to eligibility, since some "state instrumentalities" do not qualify. To obtain an application for the exemption, contact the regional IRS center.

The second step on the road to obtaining private foundation monies is to identify those foundations that award grants for programs for persons with disabilities

Your local school district has access to a variety of funds through state-administered federal monies for special education materials.

in your area. Much of this information can be found in publications such as the Foundations Directory.

Comprehensive information, however, can only be obtained at larger libraries known as "foundation depositories." A reference librarian in your area can tell you where the nearest foundation depository library is. Foundations will send you, upon request, their annual reports describing their individual procedures on applying for grants. Although this process is time-consuming, it can be very rewarding in terms of the monies received to begin an adapted device loan program at your local library.

Your local school district has access to a variety of funds through state-administered federal monies for special education materials. Whether any of these monies are shared with the school library or resource center depends on state and local school board policies. A bill was recently introduced in Congress to provide monies to states for assistive device programs for special education students, but, even if the bill is passed, it will be some time before programs are implemented.

Your child's rehabilitation facility library may qualify for Library Services and Construction Act Title I monies, administered by your state library. There are "special need" provisions beyond the formula allocations of this grant, which can be used to fund such a loan program. In fact, this is the source of funding obtained to begin this program at the New Mexico Developmental Disabilities Library.

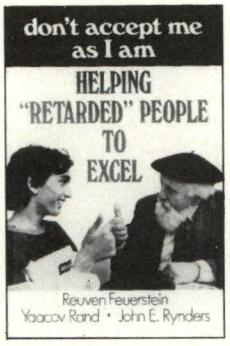
If you decide to approach your public library for this proposal, one source of partial funding may be your local Friends of the Library group. These groups, particularly in larger cities, have funds available for specific programs permitted in their bylaws.

V. Other Advantages for the Library

Libraries live by user statistics. These statistics are important in budget justifications and personnel allocation. You can point out how this program can increase user statistics, particularly for under-served populations.

The fact is that public relations programs have become very important for libraries. Show how this assistive device service can enhance the library's public relations program. Point out how the use of press releases, invitations to television stations, and the

"A beacon of hope"



Emily Perl Kingsley
writer for *Sesame Street*

DON'T ACCEPT ME AS I AM
Helping "Retarded" People to Excel
Reuven Feuerstein, Yaacov Rand, and **John E. Rynders**

"This book gives not only hope but what may be even more important—direction and guidance. . . ."
H. Carl Haywood, Vanderbilt University

"Insightful, inspirational, and instructive for laymen and professionals alike. Must reading."
Abraham J. Tannenbaum, Columbia University

These three world-renowned psychologists have originated a revolutionary new method for raising the I.Q.'s of individuals with mental retardation and Down syndrome. This is the only book to set forth their steps of "mediated learning" and how these steps may be applied to children and adults.

PLENUM PUBLISHING CORPORATION
233 Spring Street
New York, NY 10013-1578
1-800-221-9369 (212) 620-8421

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41 Taconic Ave.
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equipment shop
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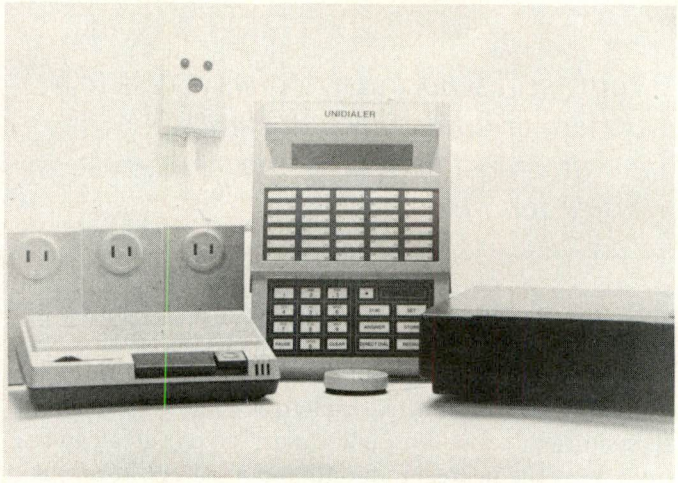


One basic single switch can access the telephone, up to four power modules and a television converter. Photo by TASH, Inc.

organization of workshops and seminars on these devices can enhance the library's image as a concerned community service provider.

SUBMITTING YOUR PROPOSAL

Your strategy in submitting your proposal will vary for the school, public, and rehabilitation facility library. Your first contact, even before writing the proposal, should be in person with the highest ranking librarian with whom you can get an appointment. Let the librarian know of your plan to make this proposal and ask for input. You might even get an offer of research assistance in writing the proposal. In fact, if you are lucky enough to encounter a progressive and dynamic librarian who has a special interest in serving the special needs of people with disabilities, the battle may be half won at this first meeting. The astute librarian will realize the many advantages in such a loan program and may volunteer to spearhead the project and follow it through with library personnel. If so, your work is virtually done. All you need to do is make periodic contact to check on the progress of the program. Unfortunately, few will have such an offer. This article is to help the majority of you who will have to follow through with the entire project.

For the school library, after your initial meeting with the head librarian, you may also want to meet with a school administrator, school board member, and your child's teachers. These people may also adopt your suggestion and initiate the proposal for you. If you need to follow through yourself with the official written proposal, contact your parents' network to recruit assistants. Research and write the proposal according to the outline presented above.

Send copies of the finished proposal simultaneously to: (1) the local school principal, administrators, and special education teachers; (2) the school librarian; (3)

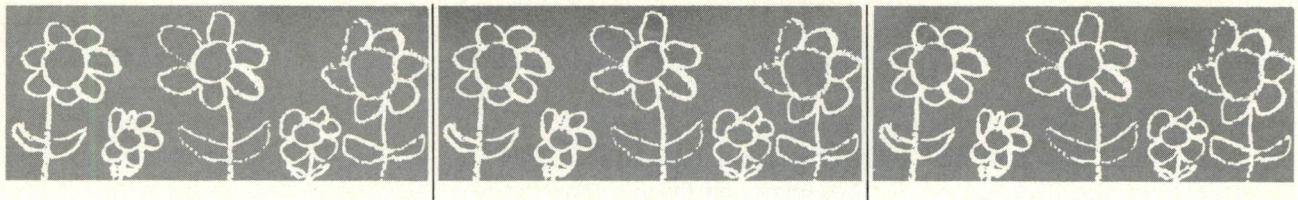
It can also be helpful to send letters to the editors of local newspapers outlining the project you are proposing. Be persistent. If you follow these suggestions closely, success is probable.

each school board member, including the superintendent; (4) local political representatives. In a cover letter sent with your proposal, ask for a written response and mention that you will be making follow-up contact to check on the progress of the proposal. After a reasonable amount of time, make your follow-up contacts. If you are turned down, or it seems you are being put off, you may want to contact your state Department of Education. Sometimes, dealing with state bureaucracy may become a lengthy process. If you fail with your school library, dust yourself off, make a note of the next school board election, gather your forces, and make an appointment with your public library administrator.

After you meet with your public library administrator, you may also want to meet with administrators in the municipal or county governmental agencies that oversee the library, as well as the president of the Friends of the Library group. With their input, and in coordination with as many interested civic groups and other allies as you can muster, prepare your proposal. If your city has a university with a special education department, include them in the process. Mail the proposal simultaneously to: (1) your public library administrators; (2) municipal or county administrators, including the mayor or county commissioner; (3) interested civic groups; (4) other local political representatives; (5) advocacy groups for persons with disabilities.

It can also be helpful to send letters to the editors of local newspapers outlining the project you are proposing, co-signed by as many influential persons as possible. Make your follow-up contacts after a reasonable period of time. Be persistent. If you follow these suggestions closely, success is probable. ♦

David Haynes obtained his master's degree in library science from the University of Texas at Austin. Until recently, he was the chief librarian for client and professional services at the New Mexico Developmental Disabilities Library. He has accepted a position at the R.F.K. Library at the University of Guam and is now residing in Mangilao, Guam.



Elementary and Secondary Special Education

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St. Coletta School, founded in 1904, offers a year-around academic residential program for mentally retarded children and adults (ages 6-25).

Other St. Coletta programs include habilitation/vocational training, adult worker, Alverno unskilled nursing care home and Coletta-James transitional group home.

Additional services enhancing the academic program include:

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- Socialization skills
- Personal living skills
- Transitional home living
- Speech and language development
- Music and art
- Adaptive physical education and swimming
- Physical and occupational therapy

for further information contact:
Sister Elaine Weber, *Administrator*
St. Coletta School
Route 1, Box 43
Jefferson, Wisconsin 53549
Telephone (414) 674-4330

BECOME AN INFORMED TECHNOLOGY CONSUMER

by Susan Elting, Nancy Meidenbauer and Nell Bailey

Today a nonverbal child speaks with the help of an electronic communication aid and a learning disabled student masters math facts using a computer game. Computers and other technology have expanded and enriched our lives and given our children options not imagined a decade ago.

However with these technology options come many decisions for the consumer, such as deciding if and when to use a computer and deciding what hardware and software to purchase. Using computers and assistive devices can prove to be expensive both in money and time invested. Technology use is forcing us to become informed consumers, critical of the limitations of technology and aware of alternate possibilities for achieving a specific goal.

Fortunately, there is a wealth of resources that parents and teachers can access. At the Center for Special Education Technology, we collect data on local, state, and national resources and have noticed a dramatic increase in the number of technology resources over the last six years.

The Center, a national information center funded by the federal government and housed at the Council for Exceptional Children, provides information on the use of technology for children with disabilities to teachers, administrators, parents, researchers, and others. In our work with these groups, we have found that consumers first need to gather some basic information and then often need additional support and services to locate and use technology to their advantage.

WHERE TO BEGIN

If you are interested in using computers or assistive technology with your child but do not know where to begin, start by reading general information on the subject. There are a number of books that have been published on technology. Some are classics such as *Microcomputer Resource Book For Special Education* by D. Hagen.

New releases offer a host of current information. Two of these are *Making an Exceptional Difference: Enhancing the Impact of Microcomputer Technology* by H. Pressman and *Breaking Barriers: How Children and Adults with Severe Handicaps can Access the World Through Simple Technology* by L. Levin and L. Scherfenberg.

SCHOOL AND COMMUNITY SERVICES

Print information alone may not be enough to help you with your technology decisions. You may need to contact agencies and organizations that provide special services. To do this, first become aware of resources that exist in your community. Local resources can supply personalized assistance to fit technology to your child.

Probably the most important community resource is the school. Your child's teacher can often help you assess the potential of using technology at home given your child's needs. The teacher may also be able to guide you in selecting appropriate software for your child. Some districts allow parents to borrow computer equipment for home use.

Another local resource is the computer users' group. User groups can provide valuable information about the use of software and hardware. Technical questions can be answered by members who are experienced with both. Check with your local computer dealer or telephone directory to find a group in your area. Computer manufacturers may also know of a local user group.

The Apple Alliance, a national network of community-based resource centers, now has centers located throughout the country. Parents are welcome to come in and see demonstrations of different hardware and software and receive assistance on using technology with their child.

SPECIFIC INFORMATION

If you are looking for information about using technology with a child with a specific disability, try contacting the local chapter of the disability organization serving that population. For example, if your child has a learning disability, contact the local Association for Children and Adults with Learning Disabilities. (ACLD).

Other organizations like the Easter Seal Societies and the United Cerebral Palsy Association often provide direct services to families and to local schools in the use of technology.

SOFTWARE AND HARDWARE INFORMATION

Your local public library can be a gold mine for information on computer hardware and software.

Some libraries set up mini computer labs for the public to use.

A number of databases provide information on software and hardware products. Closing the Gap, LINC, and the TRACE Center are just three of the groups that offer lists or directories of computer products. There is a list of publications, clearinghouses and vendors of computer and communication products in the Technology Resource Directory beginning on page 36.

Another source for software information is your local computer store. National chains such as B. Dalton and Egghead carry a good selection of instructional software for all ages. Some software companies cater to the home market. Scholastic and Broderbund issue home market catalogs so you can shop by mail.

Some parents may be able to contact special software preview centers, operated by school districts or universities. Since these preview centers cater to teachers, call first to make sure parents are welcome.

Hardware information may be harder to find locally. You may need to contact the equipment vendor directly. Prentke Romich, ComputAbility, and Don Johnston are three vendors that provide services to handicapped children by tailoring technology devices to fit individual needs.

ASSISTIVE DEVICES

Local hospitals and community rehabilitation or vocational centers may be active in designing and fitting assistive devices to complement your child's capabilities.

At the state level, some states have established assistive device centers to provide information about particular devices. For example, Pennsylvania has located an assistive device center at the Elizabethtown Hospital and Rehabilitation Center in Elizabethtown, Pa., to serve the entire state. In California, there is an assistive device center at California State University in Sacramento, Calif. Expect to see more of these centers as interest in assistive uses of technology grows.

FUNDING SOURCES

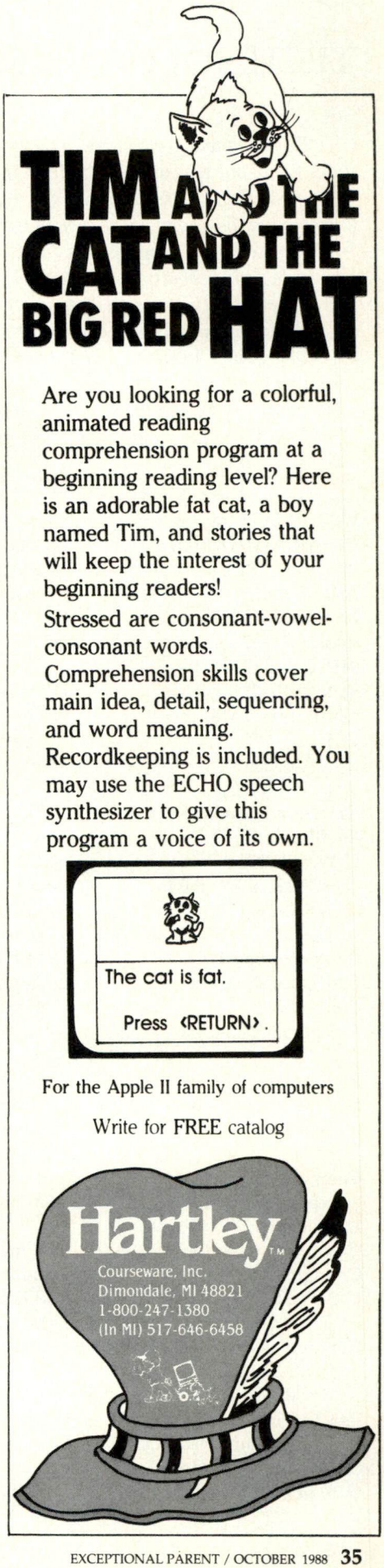
Finding funding for technology devices requires an individualized approach. To begin your search, check out resources that are available to you locally, such as the Lions or Kiwanis Clubs, and religious organizations.

Nationally, the Easter Seal Society in connection with IBM has an assistance project that allows eligible persons with disabilities to purchase discounted computer systems. Check with the National Easter Seal Society (2023 West Ogden Avenue, Chicago, Ill. 60012) for details.

Additional funding sources may soon emerge with new federal legislation and more national interest in technology by insurance companies.

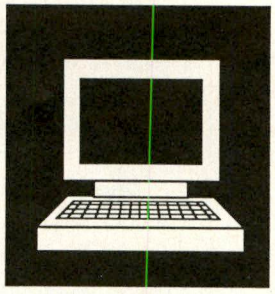
To really make technology work for you and your child, it is important to become an informed consumer. Use the abundant resources available: read about technology, talk to others who use it, and try out various technology options before you buy.

Center for Special Education Technology staff members Susan Elting, Nancy Meidenbauer and Nell Bailey contributed to this article for Exceptional Parent. Center for Special Education Technology, 1920 Association Ave, Reston, Va. 22091: (800) 873-TALK or (800) 345-TECH



TECHNOLOGY RESOURCE DIRECTORY

This Technology Resource Directory is included as a guide for all our readers. It contains a listing of Information Clearinghouses, Publications and a directory of Commercial Vendors that lists companies (vendors) that market computer hardware, software, adaptive aids and communication devices for people with disabilities. The symbols following the name and address of each company summarize the information we have obtained from each company. The symbols indicate 1) the types of products available; and 2) the types of disabilities served by the products. For specific details, contact the vendor and say you read about them in the EXCEPTIONAL PARENT Technology Resource Directory.



INFORMATION CLEARINGHOUSES

ABLEDATA
National Rehabilitation Information Center
8455 Colesville Road
Suite 935
Silver Spring, Md. 20910
(301) 588-9284
(800) 346-2742

American Foundation for the Blind
15 West 16th St.
New York, N.Y. 10011
(212) 620-2143

Center for Special Education Technology
Council for Exceptional Children
1920 Association Dr.
Reston, Va. 22091
(800) 345-TECH
(800) 873-TALK

Committee on Personal Computers and the Handicapped (COPH-2)
2030 Irving Park Road
Chicago, Ill. 60618
(312) 866-8195

CompuHelp
International Blind Users Group, (IBUG)
P.O. Box 1352
Roseville, Calif. 95661-1352
(916) 786-3923 (Modem)
(916) 645-8036 (Voice)

CompuServe
P.O. Box 20212
5000 Arlington Centre Blvd.
Columbus, Ohio 43220
(614) 457-8600
(800) 818-8199

DEAFNET
SRI International
333 Ravenswood Ave.
Menlo Park, Calif. 94025
(415) 326-6200
(415) 859-4771

ERIC Education Research Information Center
4350 East West Highway, Suite 1100
Bethesda, Md. 20814
(301) 656-9723

National Clearinghouse on Rehabilitation Training Material
Oklahoma State University
115 Old USDA Bldg.
Stillwater, Okla. 74078
(405) 744-7650

National Support Center for Persons with Disabilities
IBM Educational Systems
25 Windy Ridge Parkway
Marietta, Ga. 30067
(800) IBM-2133

Office of Special Education Program
Apple Computer Inc.
19925 Stevens Creek Blvd.
MS 43-F
Cupertino, Calif. 95014
(408) 974-7910

Special Education Software Center
LINC Resources, Inc.
4820 Indianola Ave.
Columbus, Ohio 43214
(614) 885-5599

SpecialNet
National Association of State Directors of Special Education
2021 K St. NW, Suite 315
Washington, D.C. 20006
(202) 296-1800

Technical Resource Center
525 Eleventh Ave. S.W., Suite 100
Calgary, Alberta
Canada T2R 0C9

Trace Research and Development Center
Room S-151 Waisman Center
1500 Highland Ave.
Madison, Wis. 53705
(608) 262-6966

PUBLICATIONS

Augmentative and Alternative Communication Journal
c/o Williams & Wilkins
428 E. Preston St.
Baltimore, Md. 21202
(301) 528-4000

The CATALYST
W. Center for Microcomputers in Special Education
1259 El Camino Real, Suite 275
Menlo Park, Calif. 94025
(415) 326-6997

Closing the Gap
P.O. Box 68
Henderson, Minn. 56044
(612) 248-3294

Communication Outlook
Artificial Language Laboratory
405 Computer Center
Michigan State University
East Lansing, Mich. 48824
(517) 353-0870

Computer Disability News
National Easter Seal Society
2023 W. Ogden Ave.
Chicago, Ill. 60612
(312) 243-8400

Computing Teacher
The International Council for Computers in Education
University of Oregon
1787 Agate St.
Eugene, Ore. 97403-1923
(503) 686-4414

COPH Bulletin
2030 Irving Park Road
Chicago, Ill. 60618
(312) 866-8195

Education Computer News
c/o Business Publishers
951 Pershing Drive
Silver Spring, Md. 20910
(301) 587-6300

Journal of Special Education Technology
Special Education Dept.
Vanderbilt University
Box 328
Nashville, Tenn. 37203
(615) 322-8150

COMMERCIAL VENDORS

Key to Symbols used in the directory:

Vendor Products
AA = Adaptive Aid
CA = Communication Aid
H = Hardware
S = Software

Disability Codes
HI = Hearing Impaired
LD = Learning Disabled
IE = Intellectual or Emotional Disability
PH = Physical Disability
SI = Speech Impairment
VI = Visual Impairment

Computer Compatability
A = Apple
IBM = IBM
Ω = Commodore
RS = Tandy
å = Atari
Σ = Other systems (Franklin, Lazer, Compaq, Toshiba, PS, PS2-30, Vic 20, System II, DEC Rainbow)

For specific details, contact the vendor and say you read about them in the EXCEPTIONAL PARENT Technology Resource Directory.

COMPUTER PRODUCTS

AbleNet [A]
360 Hoover St., N.E.
Minneapolis, Minn. 55413
(612) 331-5958
AA, H, IE, PH

Abracadata, Ltd. [A, IBM]
P.O. Box 2440
Eugene, Ore. 97402
(503) 342-3030
S, HI, LD, IE, PH, SI

Access Unlimited-SPEECH Enterprises [A, IBM]
9039 Katy Freeway,
Suite 414
Houston, Texas 77024
(713) 461-1666
S, HI, LD, IE, SI, VI

ACTT (Activating Children Through Technology) [A]
Project ACTT
27 Horrabin Hall
W. Illinois University
Macomb, Ill. 61455
(309) 298-1014
S, CA, LD, IE, PH, SI,

ADAMLAB [A]
33500 Van Born Road
Wayne, Mich. 48184
(313) 467-1415
CA, H, LD, IE, PH, SI

Adaptive Peripherals [A]
4529 Bagley Ave. N.
Seattle, Wash. 98103
(206) 633-2610
AA, H, S, LD, IE, PH, VI

Advanced Ideas, Inc. [A, IBM, Ω, RS, Σ]
2902 San Pablo Ave.
Berkeley, Calif. 94702
(415) 526-9100
S, HI, LD, IE, SI

American Educational Computer, Inc. [A, IBM, Ω, RS, å]
7506 N. Broadway Extension,
Suite 505
Oklahoma City, Okla. 73116
(800) 222-2811
S, HI, LD, IE, SI, VI

American Printing House for the Blind [A, IBM]
P.O. Box 6085
Louisville, Ky. 40206
(502) 895-2405
H, S, PH, VI

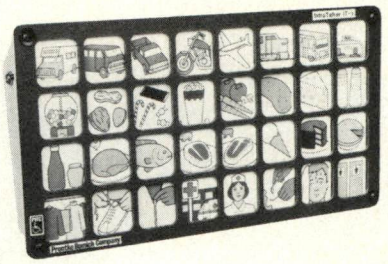
Amidon Publications [A]
1966 Benson Ave.
St. Paul, Minn. 55116
(612) 690-2401
(800) 328-6502
S, HI, LD, IE, SI

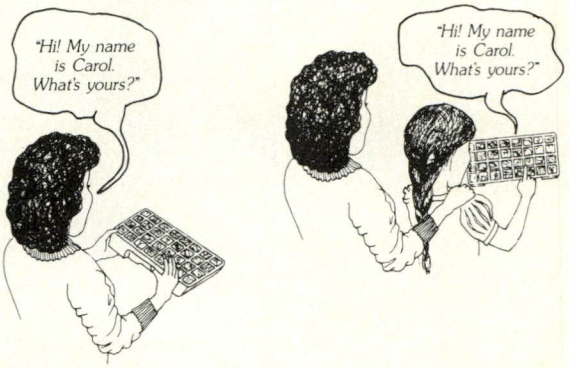
Animated Voice [IBM, RS, Σ]
P.O. Box 819
San Marcos, Calif. 92069
(619) 744-8190
(800) 942-3699
CA, H, HI LD, IE, SI

Prentke Romich Company
introduces

IntroTalker

Introductory speech output communication aid





- Natural speech quality
- Allows sequencing (limited form of Minspeak™)
- Small size (13" x 7" x 3") & weight (5 lbs.)
- Low cost ($595)
- Trade-in policy for higher performance PRC Touch Talker

Caution: Personal achievement at risk!
Speech quality and cost do not generally affect personal achievement. Please do not purchase this device for individual use on the basis of either of these factors. IntroTalker is intended as an introductory device, with most users quickly moving up to a higher performance Minspeak system.

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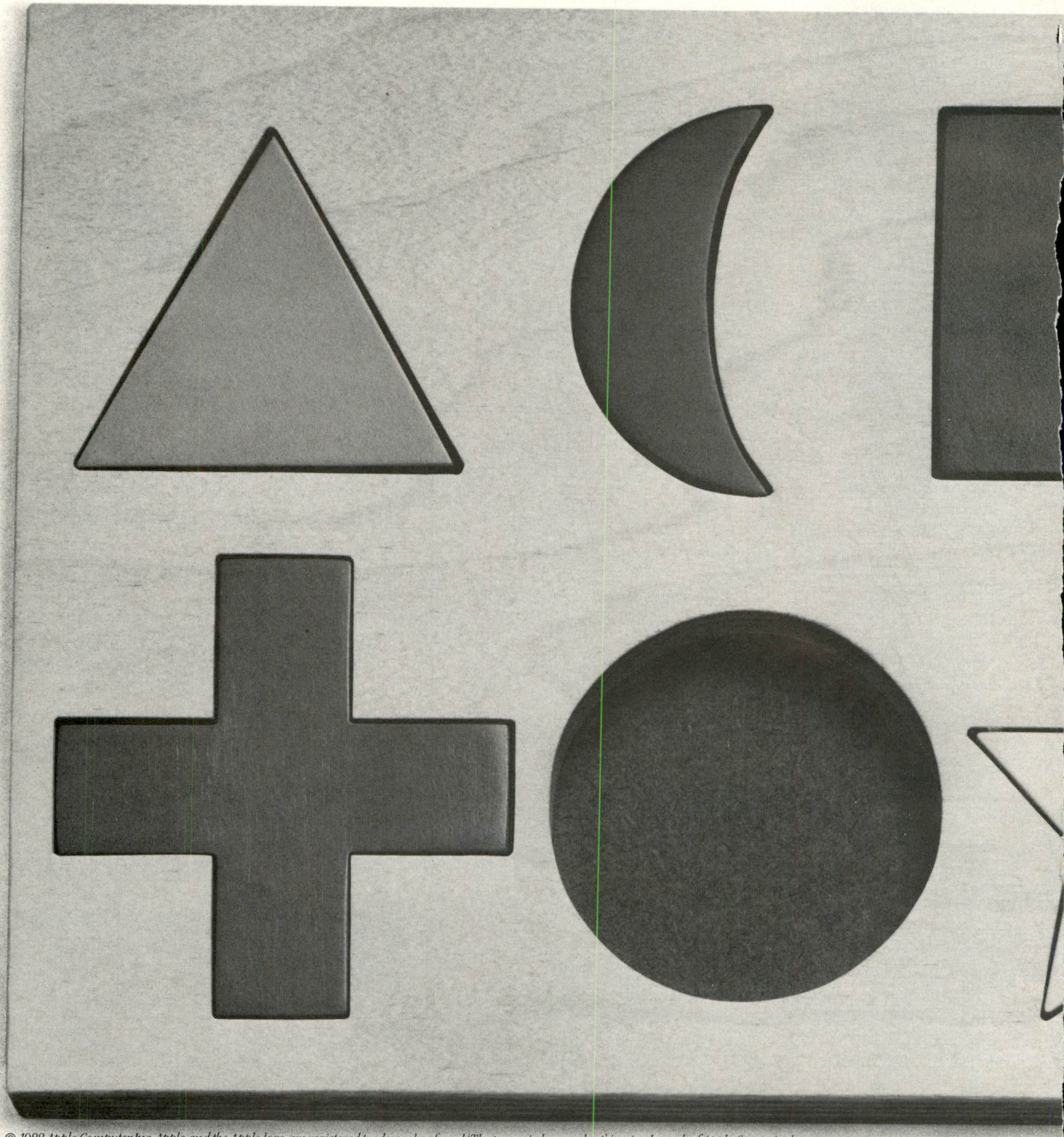

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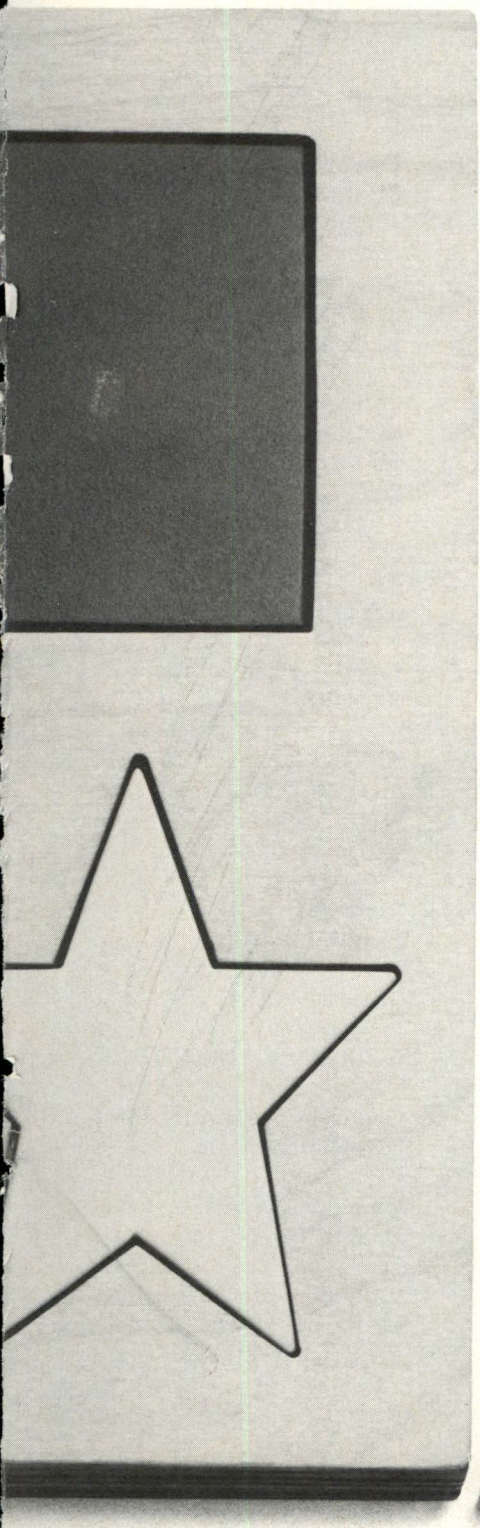
we're working on it.



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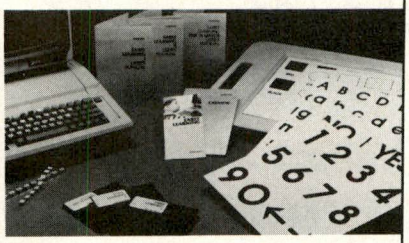
A child's potential deserves to be developed



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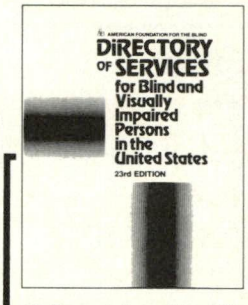

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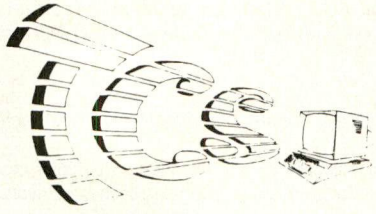

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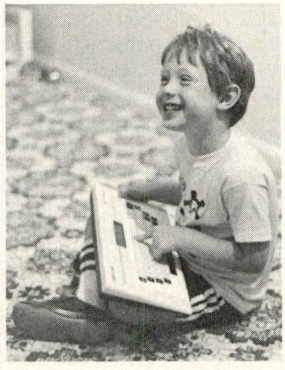

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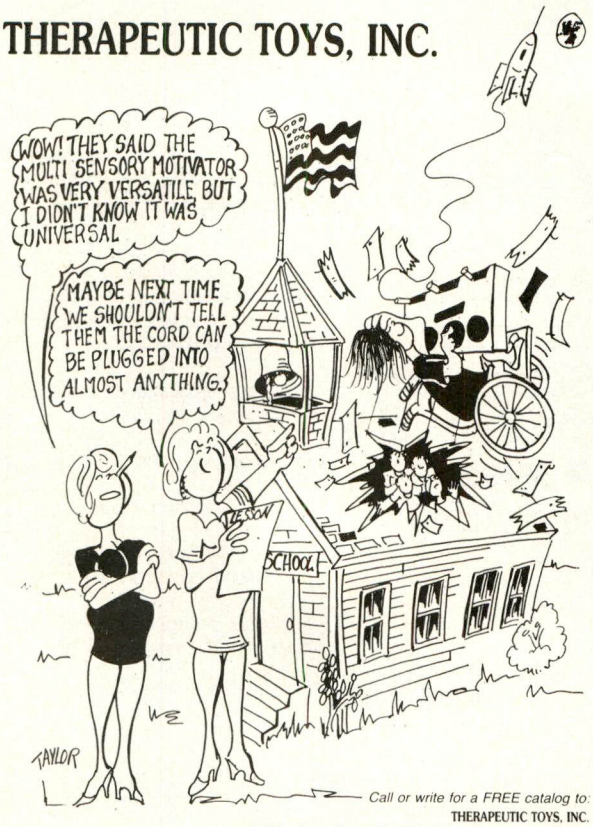

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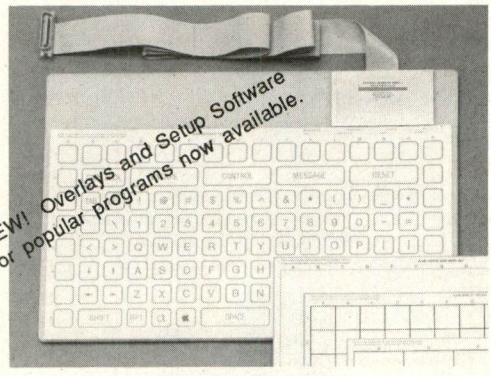

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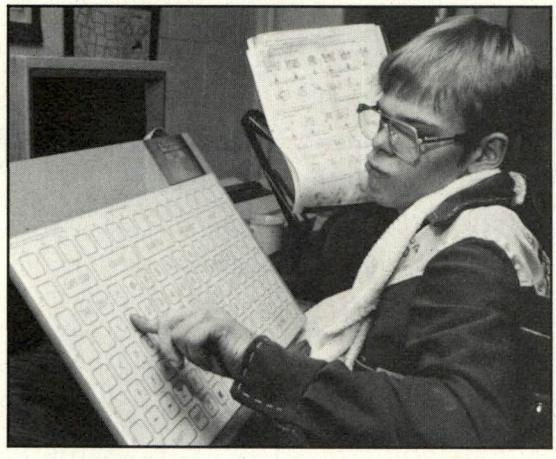

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National
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The National Special Education Alliance: One Year Later

An update on the National Special Education Alliance.

by
Peter Green

"Expectations are soaring," claimed Apple Computer, Inc. when it announced the formation of a national network of local computer resource centers called the National Special Education Alliance (NSEA). The alliance was composed of 11 non-profit, parent-run sites closely linked by a common passion: to use state-of-the-art technology to better the lives of individuals with disabilities.

Today the alliance has more than doubled in size. There are now two dozen support centers located across the United States. One year ago *EXCEPTIONAL PARENT* reported on NSEA to parents and professionals.

A BRIEF HISTORY

The NSEA exists today largely due to the vision and energy displayed by two groups: Apple Computer, Inc. and the Disabled Children's Computer Group (DCCG) in Berkeley, Calif. In late 1986, Apple was continuing to build the Office of Special Education Programs it had created just a year before. And the DCCG was a small, non-profit agency doing not-so-small things with computer technology and people with disabilities. In fact, DCCG was enormously successful in implementing community programs to help local users become aware of adaptive technology. The staff at DCCG distributed information, held training workshops, led product demonstrations and worked closely with technology developers. Before long employees at Apple Computer began hearing about DCCG, and in the summer of 1986 the two groups were officially introduced.

The result of a series of meetings was a model for a national network of locally based DCCG-like resource centers. That model would be called the National Special Education Alliance. The long-term goal would be to develop at least one such community based, parent-driven, technology resource center in every state. Initially, eleven Charter Member Resource Centers were chosen to form the alliance.

THE ALLIANCE TODAY

As the alliance enters its second year, many centers -- both old and new -- are discovering the benefits of being part of a large network of support. According to Jackie Brand, NSEA executive director, "Each center has its individual strengths and specialties, and that expertise is rubbing off on all the other sites across the country." As a result, all of the member sites are better able to serve a broad range of ages, needs and disabilities. Instead of concentrating on just one area of interest, many centers are working closely with their colleagues to become fluent in many different disciplines. Carol Cohen of the Computer Center for Independence Training and Education in Florida says, "Although our center specializes in visual impairments, we feel we have the resources and connections to find answers concerning just about any kind of disability."

All the centers are non-profit agencies, staffed largely by volunteers. Many of the centers are located in donated buildings -- schools, public libraries, or local agencies. The unifying characteristic of all the centers is their ability to effectively respond to questions and raise awareness about

today's adaptive computer technology. To this end, all the sites disseminate information, hold training workshops, provide hands-on computer exploration time and help local computer users with disabilities make their own decisions about the most useful adaptive equipment. Many sites are setting up lending libraries to allow local users with disabilities a chance to sample adaptive equipment in their own homes. Several sites offer individual consultations to parents, training workshops for children and software evaluations for educators.

Another important similarity among sites is the absolute belief that parents -- along with professionals and consumers -- must be key leaders in the decision-making process. Indeed, one of the basic requirements for being accepted for NSEA membership is that the agency have strong parent and consumer involvement along with solid professional support.

From the NSEA's inception, it was expected that these centers would actively go out and make a difference in the world. But no one came close to guessing the *extent* of that impact. A recent survey conducted by Apple Computer shows that every month the NSEA reaches more than 1000 computer users with disabilities. The typical center reported receiving nearly 150 phone calls per month. And the average NSEA center has a mailing list of over 800 members.

BUILDING A NETWORK

Before the NSEA became a network, many of the centers operated as independent resource sites working alone in their community. "We had the feeling that we were alone in the world," says Pat Cashdollar of the Communication Assistance Resource Service (CARS) in Ohio. "We had no idea that there were other centers out there who were interested in the same goals we were." Today, one of the most important items on the alliance's agenda is to maintain a state-of-the-art level of networking and communicating among centers. To achieve this, each site is linked "electronically" to all the other centers, allowing for split-second communication and information sharing.

Using AppleLink®, Apple Computer's computer-based mail system, a center in Missouri, can send an electronic note to a site in Colorado in less than 10 seconds -- or even a note to every NSEA center in that same time frame. For example, in a recent communication, the Disabled Citizen's Computer Center (DCCC) in Kentucky sent a message to all of the other alliance centers asking for advice about how to best adapt a computer to help a six-year-old child with cerebral palsy. Bob Glass of DCCC said, "We didn't know how best to help this child. By the next morning we had received no less than five solid suggestions from other NSEA sites."

The NSEA is constantly exploring new methods of communication. Most recently the group has been experimenting with an electronic bulletin board system called GrantLink. Instead of addressing electronic memos to specific members of the group, the computer bulletin board allows NSEA members to "tack up" a message or question for all alliance members to see. In addition to posting electronic messages, GrantLink has a built-in library of information useful to non-profit agencies. For example, the system contains information on everything from funding tips and creating newsletters, to the latest news in the education field. Because of this vast collection of on-line material, GrantLink plays an important role in supporting each center. As Brand describes, "Telecommunications allows us immediate and ongoing contact with each other. We can be instantly responsive to the needs at our centers."

All the centers are non-profit agencies, staffed largely by volunteers.

Photo by Apple Computer, Inc.

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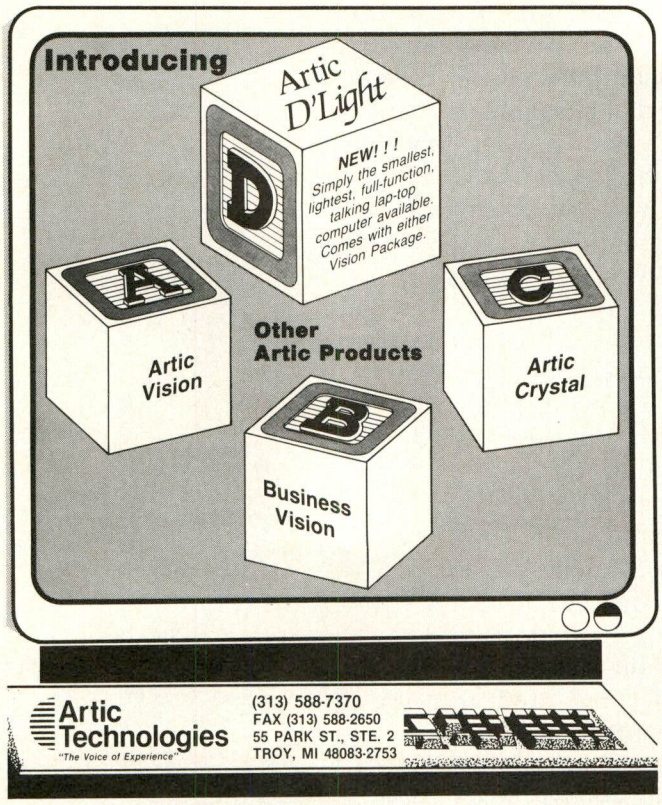

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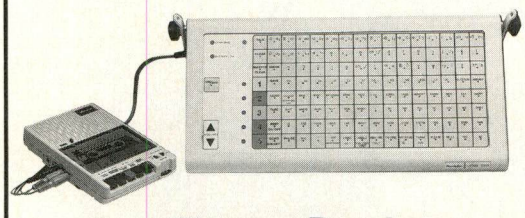

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The NSEA at work.

- **KENTUCKY:** The Center for Adaptive Technology and Education (CATER) is working on a program with the University of New Orleans to assist teachers, administrators and parents in the process of integrating students with moderate to severe disabilities into the mainstream school campuses. This summer, the CATER center has established a "Computer Club," which will enable kids with disabilities to interact with their friends from the new schools in a supportive environment.

- **CALIFORNIA:** The Computer Access Center is experimenting with a new program called "Kids Teaching Kids" in which local children are given free reign over the computer equipment to experiment, play, learn and teach their friends. As new members come into the center, the "experts" will be available to give first-hand instruction on adaptive tools.

- **MONTANA**: The Parents, Let's Unite for Kids (PLUK) center is currently setting up its own telecommunication network for families of kids with disabilities who live in remote, rural locations. Using modems and computers to communicate, the center is finding an exciting way to tie together a group of otherwise very isolated individuals.

- **MISSOURI**: The Computer Resource Center is experimenting with a "Software Swap" program whereby local computer users can trade with center members their personal software packages. The swap project enables a broad audience of computer users to demonstrate and experience expensive software tools.

BRINGING THE GROUP TOGETHER

Saturday, July 30, 1988 was a landmark day in the history of the NSEA. It was the first time that individuals from all 24 centers met together for an evening -- not electronically, but physically. The event took place at Harvard University's Graduate School of Education. Members from each resource center came to participate in training for one week.

For the newest members of the alliance, the training provided a chance to come up to speed with the other sites. More experienced centers worked with newer sites to help them become familiar with adaptive computer tools, assist them with AppleLink and to share tips about how to run a successful resource center.

PREPARING FOR THE FUTURE

Pressing issues regarding the future growth of the alliance remain. "We're looking not only in terms of growth in the number of centers," comments Brand, "but growth in the level of support and quality that each center brings to the alliance."

Lately the NSEA has been working diligently to foster close working relationships with the business community. Partnership with the business community appears to be beneficial for all involved. Vendors have supported the local sites by providing up-to-date product information, assisting with software demonstrations and being responsive to customer feedback. The relationship has also been beneficial to vendors as well because sites have tested products and provided input on new solutions.

As the alliance continues to grow in the number of centers and vendors in the network, and in the expanded support it offers, individuals with disabilities all across the country will benefit enormously. "Expectations *are* soaring," says Brand. "With the advent of exciting, powerful technologies, we're expecting to help more and more children and adults with disabilities."

Apple Computer agrees. In a recent corporate advertisement promoting the NSEA, the headline reads, "Life isn't fair. But we're working on it." That, in a nutshell, describes the mission of the NSEA. ♦

For more information about the National Special Education Alliance, contact Apple's Office of Special Education, 20525 Mariani Ave., Cupertino, Calif. 95014.

Peter Green works in the Office of Special Education at Apple Computer, Inc., Cupertino, Calif.

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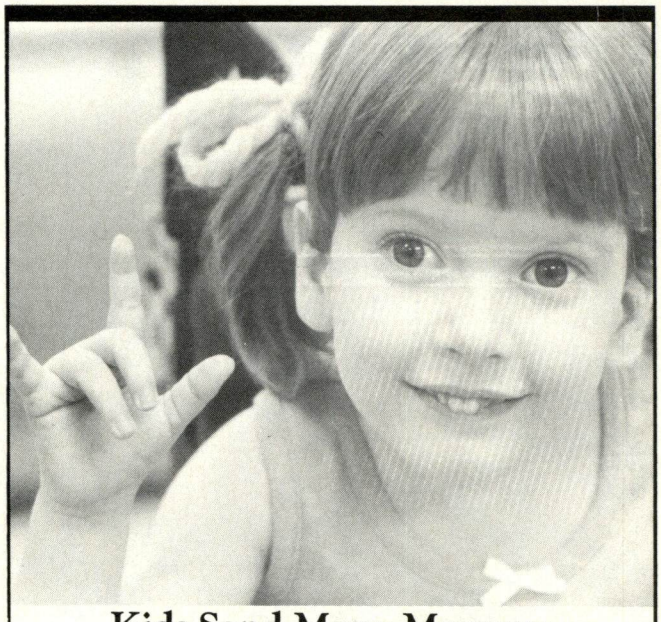

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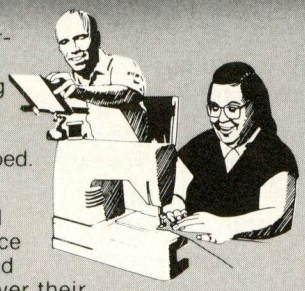

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No Longer "Just a Parent:" The Role of Parents in the NSEA

by Lisa Cohn and Peter Green

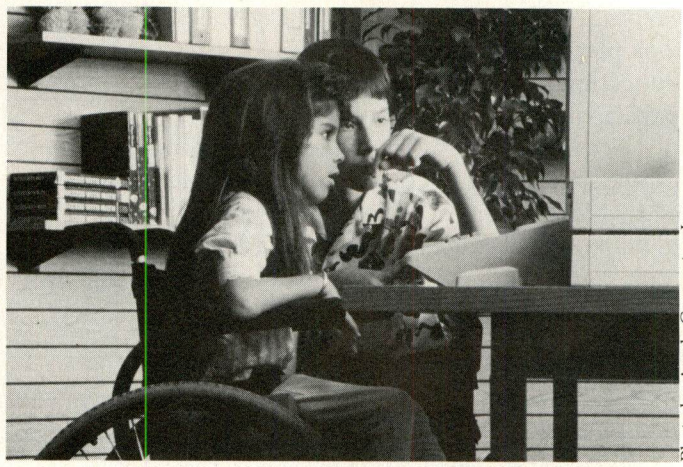

Photo by Apple Computer, Inc.

Many parents of children with disabilities would like to change the world -- the way people in the world see their child, the often "prescriptive" relationship between professionals and parents, and perhaps most of all the way parents, themselves, are perceived as *consumers* of help rather than *providers* of support.

All too often a parent of a child with disabilities is seen as being "just a parent." Quiet. Meek. Brave. Powerless. Forever cheering their child on from the sidelines. We all know that this traditional, stereotypical "telethon" image has never been true. Through the individual efforts of many dedicated and persistent parents the world is, in fact, slowly beginning to change.

Indeed, in the 24 NSEA technology resource centers across the country, mothers and fathers are the leading force in dreaming, planning, designing, and building a bright future for their kids. No longer are parents waiting for well-intentioned experts to create new possibilities for their children through technology. Instead, in every NSEA center, the notion of parent-as-leader is the rule rather than the exception.

As many parents are quickly discovering, technology is powerful in ways beyond what computers can do for their children -- it's changing the way they are able to relate to professionals. Because computer technology is unfamiliar to vast numbers of people, parents and professionals alike are finding themselves on equal ground. No one group can claim expertise, making way for a true collaborative relationship where everyone can learn about and explore exciting new possibilities together.

This collaborative relationship was plainly evident at a recent training seminar for NSEA leaders. During the training, parents and professionals worked together to solve problems and learn the latest technology.

Unlike many "academic" or "medical" conferences where parents often play little or no role, the seminar opportunity enabled parents to stand on equal footing with their professional colleagues. Nonetheless, one of the most rewarding aspects was the chance for parents to connect with other parents who started NSEA sites.

As parents across the country work at building technology resource centers to help their children, they are finding many experiences to be personally powerful and rewarding. In a number of cases, this new state-of-the-art technology has served as a new answer for parents who have been asking themselves for too long the question "How can I best help my child?" Many parents are finding that the computer technology offers them a chance to work with their child alone, without constant guidance from therapists and teachers.

Other parents are seeing new possibilities and expectations for their child through the filter of adaptive technology. "Now I understand my son's use of a wheelchair and the Touchwindow as tools that empower him more effectively in the world," says Greg Burkett of the Computer Center for Independence Training and Education (CITE) in Orlando, Fla. and father of four-year-old Michael. "Just two short years ago, the school system was having trouble assessing him or placing him in school. Now they are intrigued with his progress, but still debate what he can learn or accomplish. While they debate, CITE is equipping us with learning activities and always trying new software and adaptive hardware to keep Michael challenged and to discover what works best with his slight vision problem and severe muscle impairment."

Still other parents are feeling a strong sense of competence as they work with emerging computer technology. The harnessing of a personal passion for changing their child's life through technology has made many parents want to reach beyond their personal quest to help others. This feeling is especially evidenced by Jackie Brand, executive director of the NSEA. She and her husband, Steve, started the first NSEA computer site in Berkeley, Calif. in 1985 as an outgrowth of their efforts to help their thirteen–year–old daughter, Shoshana. Now Brand is working on a national level to help other parents develop technology resource centers based on a firm foundation of parental leadership.

The NSEA's powerful focus on technological solutions and the collaborative problem solving team has enabled parents across the country to begin to change the world for their children. With the help of adaptive technology, children with disabilities are now setting and reaching new goals. And in the process their parents are playing a critical role in determining the future for their children. ♦

Lisa Cohn is the founder of the Special Technology Center in San Jose, Calif. She is the parent of Matt, age five, who has cerebral palsy, and Alex, who is ten months old.

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NSEA Members Centers

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CALIFORNIA: Computer Access Center, 2425 16th St., Room 23, Santa Monica, Calif. 90405. Contact: Donna Dutton, (213) 450-8827; **Disabled Children's Computer Group**, 2095 Rose St., Berkeley, Calif. 94709. Contact: Alice Wershing, (415) 841-3224; **Special Technology Center,** Division of Parents Helping Parents, 535 Race St., Suite 220, San Jose, Calif. 95126. Contact: Lisa Cohn, (408) 288-5010

COLORADO: Children's Hospital Resource Center, 1056 East 19th Ave., Denver, Colo. 80218-1088. Contact: Ann Grady, (303) 861-6250

DISTRICT OF COLUMBIA: Parents Reaching Out Services,* D.C. General Hospital, Pediatrics Building, 1900 Massachusetts Ave., S.E., 4th Floor, West Wing, Washington, D.C. 20003. Contact: Gloria Stokes, (202) 546-8847

FLORIDA: Computer C.I.T.E., 215 E. New Hampshire, Orlando, Fla. 32804. Contact: Carol Cohen, (407) 299-5000 ext. 3291

GEORGIA: Parents Educating Parents, 1851 Ram Runway, Suite 102, College Park, Ga. 30337. Contact: Bonnie Wootten Webb, (404) 761-2745

ILLINOIS: Technical Aids & Assistance for the Disabled Center (TAAD), 1950 West Roosevelt, Chicago, Ill. 60608. Contact: Margaret Pfrommer, (312) 421-3373

IOWA: YWCA/R.E.A.D.I., 318 Fifth Street, S.E., Cedar Rapids, Iowa 52401. Contact: Phil White, (319) 365-1458

KANSAS: Technology Resources for Special People, 3023 Canterbury, Salina, Kan. 67401. Contact: Marjorie Hargis-Delker, (913) 827-0301

KENTUCKY: Disabled Citizens Computer Center, Louisville Free Public Library, 301 West York St., Louisville, Ky. 40203. Contact: Bob Glass, (502) 561-8637

LOUISIANA: Supergroup/CATER—Center for Adaptive Technology & Education, 3340 Severn Ave., Suite 200, Metairie, La. 70002, Contact: Melanie Ferrand, (504) 888-8964 or (504) 561-8713

MASSACHUSETTS: Massachusetts Special Technology Access Center, P.O. Box J, Bedford, Mass. 01730. Contact: Kathy Huggins, (617) 433-5434

MICHIGAN: Living and Learning Resource Center, Physically Impaired Assoc. of Michigan, 601 W. Maple St., Lansing, Mich. 48906. Contact: Donna Heiner, (517) 487-0883, (800) 833-1996 (Mich.)

MINNESOTA: Pacer Center, Inc., 4826 Chicago Ave. South, Minneapolis, Minn. 55417-1055. Contact: Daniel Berks, (612) 827-2966

MISSOURI: Computer Resource Center, St. Louis Easter Seal Society, 1710 Mississippi Ave., St. Louis, Mo. 63104. Contact: Nancy Lacey/Sue Uknes, (314) 776-1996

MONTANA: Parents, Let's Unite for Kids (PLUK), 1500 North 30th St., Billings, Mont. 59101-0298. Contact: Katharin Kelker, (406) 657-2055

NEVADA: Nevada Computer and Technology Center for the Disabled, 819 Las Vegas Blvd., South, Las Vegas, Nev. 89101. Contact: Doreen Moore, (702) 382-3358

NEW YORK: Techspress, Resource Center for Ind. Living, 401 Columbia St., Utica, N.Y. 13502. Contact: Russ Holland, (315) 797-4642 (voice or TDD)

OHIO: Communicaton Assistance Resource Service (CARS), 3201 Marshall Road, Dayton, Ohio 45429. Contact: Pat Cashdollar/Terry Trzaska, (513) 298-0803; **SpeciaLink**, 2512 Canterbury Ave., Cincinnati, Ohio 45237. Contact: Walter and Elaine Hackett, (513) 531-9233

TENNESSEE: East Tennesee Special Technology Access Center,* Dept. of Special Services Education, 325 Claston Addition, Knoxville, Tenn. 37966-3400. Contact: Lois Symington, (615) 974-6228; **West Tenn. Special Technology Resource Center for the Disabled**, 227 McCowat/P.O. Box 3683, Jackson, Tenn. 38303. Contact: Margaret Doumitt, (901) 424-9089

* Indicates newest members of the National Special Education Alliance. These centers will be providing services in the near future.

Bridging The Technology Gap

Computer technology is enabling children and adults to live fuller richer lives. Many parents feel helpless learning or evaluating information about this developing technology. They describe their frustrations about these new products and seek advice from many of the education and health professionals who serve their children.

Many of us did not grow up at a time when computers were being introduced in schools. We still feel uncomfortable when adults, much younger than us, or our children tell us about computers. We have little free time and opportunity to utilize these devices, try them out and learn how they can help us.

For the past six years, we have provided our readers with information about computer technology and the ways in which it can facilitate the growth and development of children with disabilities. We have endeavored to demystify the computer and other technologies, as well as their potential. We have also tried to share the problems along with the opportunities that these advances present.

In the last year, through an EXCEPTIONAL PARENT survey that many readers answered, we found out that over half of the readers who responded have personal home computers for their children. We learned that the experience of our readers parallels the experience of all parents. In addition, we learned that many parents have been instrumental in introducing computer technology, not only to the schools their children attend, but to the educators in their child's classroom.

We have also been made aware of the gap that exists between those health and education professionals who are developing and using technology, and the vast majority of their colleagues. Unfortunately, there are limited opportunities for practitioners to learn about and evaluate these new developments.

We have always believed the central issue for all parents in their relationship with professionals is to establish a climate of trust. The technology revolution can intrude on the issue of trust. Parents are often uncertain as to whether their children's schools know how to apply the educational technology that could maximize their children's education. The same problem arises when families try to get the best health care services -- the professionals are often unable to reassure them.

The National Special Education Alliance has developed a model for helping parents learn about and apply the advances in computer technology. Their information networks provide people with a way to learn about new developments in many fields.

Although no one planned it this way, learning about the new technological advances that can enrich lives has helped to change the relationship between parents and professionals. (See page 48.) They have become equal participants -- many are naive beginners, some are knowledgeable experts. Together these groups are breaking new ground and rapidly sharing their discoveries via telecommunication. The NSEA has also demonstrated that everyone benefits when parents have the major organizational control over an educational process. This is a striking contrast to so many educational programs developed by professionally dominated groups who usually serve only their "members" and rarely serve parents or people with disabilities.

We look forward to the future activities of these new collaborative groups. They are already providing opportunities for consumers to observe and "try out" various products -- a critical need of parents everywhere. They are also beginning to address the monumental task of identifying the products that actually provide educational or therapeutic opportunities with the needs they serve. For example, without these efforts, individual parents who have invested in personal home computers would be at a loss to find out which software products will be helpful because much of the existing software, while advertising educational value, seems to offer only arcade-type fun.

Many school systems and clinical settings have invested in computer hardware and software only to find that like so many other "new tools," the materials have not been used or maintained. Now, thanks to the pioneering efforts of parents, professionals and progressive companies across the country, that kind of history need not be repeated.

This is our sixth annual technology issue. Each year we feel overwhelmed at the prospect of choosing material and wondering whether the ideas will be practical. That is but one reason why we are so excited by the efforts we have reported on in this issue. People are sharing new knowledge so that new ideas can be enhanced. In the past, there were very few established networks and people were not aware that "the wheel had already been invented." As parents and professionals share learning experiences, they are discovering how similar their concerns and experiences actually are when trying to address the needs of children. And, as part of the same process, because parents and professionals are learning to work together and trust one another, we can look forward to progress in areas beyond technology.

- M.J.S. & S.D.K. -

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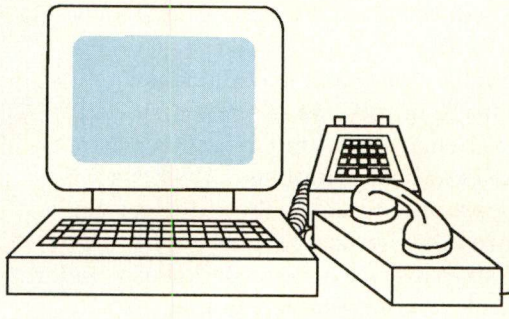


Access special needs services through your home computer.

By
Jack Moore

Computer technologies can benefit persons with physical, sensory, or mental impairments. Success stories abound. A non-vocal student actively participates in class by using a portable computer equipped with a speech synthesizer; a blind professional has become more productive using a desktop computer hooked up to a Braille printer; a learning disabled youngster is mastering new academic skills with the aid of an innovative software program.

As inspiring as these success stories are, they often do not tell the real story: the challenges that persons with special needs must overcome everyday to fully participate in the computer generation. Seldom do we hear about the difficulty of finding a low-cost speech synthesizer that really works well, an affordable Braille printer that is reliable and easy to operate, or a software package that was fun to use and instructionally sound.

Fortunately, many government and private-sector organizations are coming to the rescue by establishing information reference and referral services that can help persons with special needs to tap the power of the new computer technologies. These services assist computer users to maintain lists of product manufacturers and software publishers and provide them with hardware and software product descriptions. The services also offer helpful tips on selecting and installing specialized equipment and can refer the computer user to other sources of information.

IBM/SPECIAL NEEDS EXCHANGE

One of these new public information services is the IBM/Special Needs Exchange. IBM, like many of the major computer companies, has established corporate programs to help persons with special needs to use computer technology productively. The Exchange is operated for IBM's Special Education Programs Department by LINC Resources, Inc., a non-profit organization recognized nationally for providing information services to the regular and special education communities.

The IBM/Special Needs Exchange is a new breed of information service. That is, the Exchange is an "online information resource." Users must have a computer equipped with a modem and telecommunications software to take full advantage of all the Exchange's services. Although not everyone who owns a computer has a modem, the use of telecommunications is growing rapidly among computer users, and modems are fast becoming standard equipment for a computer work station. The Exchange may not be able to serve everyone who has a special need, but the new service is an important and innovative development nonetheless.

The IBM/Special Needs Exchange currently has two major components. First, it has a set of activities that takes place on the CompuServe Information Service -- a

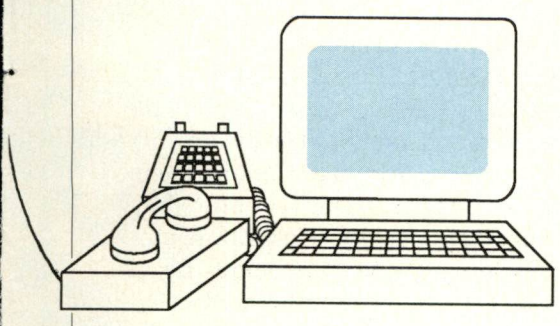
national, consumer-oriented information services network. Second, the Exchange has a dial-in database of special education software for IBM and compatible computers.

The Exchange's current "electronic home" for most of its services is the Education Forum on CompuServe. The Education Forum has three basic features: a message board that allows users to communicate with each other or with the forum manager through public and private messages; a library of text and program files that can be downloaded to the user's computer; and a conference room that allows users to "talk" to each other, or special guest speakers, in "real time" through their computer terminals.

The CompuServe activities are supplemented by two searchable, online databases set up on a dial-in system at LINC headquarters in Columbus, Ohio. One is a database of educational software available directly from IBM Corporation; the other is a database of special education software from third-party publishers. Users can conduct their own searches of these databases to identify software products that meet specific needs.

ONLINE SERVICES

As an online information resource, the IBM/Special Needs Exchange offers several important advantages over more traditional services. Perhaps most important is the



TELECOMMUNICATIONS TERMINOLOGY GLOSSARY

DOWNLOADING
Refers to the electronic transfer of information from the host computer to the user's computer. Such information may be a text file or even a software program. Data can also be "uploaded" from the user's computer to the host computer.

MODEM
A device that allows one computer to "talk" to another. The word "modem" comes from the technical terms MOdulate and DEModulate.

ONLINE DATABASE
A database, or a computerized file of information, that can be accessed remotely with a computer and a modem.

ONLINE INFORMATION SERVICE
An interactive service in which the user can access needed information through a telecommunications link. Information services such as databases, electronic mail services, online shopping services, and discussion forums are just a few of the many types of information services that are available to persons with a computer modem.

PUBLIC DOMAIN SOFTWARE
Software that is not copyrighted. It belongs to the "public domain" and is therefore free of charge to the user. Software may also be "shareware" or "user-supported;" such software is obtained for free, but users are expected to submit payment to the author on the "honor system."

TELECOMMUNICATIONS
Typically refers to the concept of computer-to-computer communications, but it also refers to the general concept of transmitting information by linking various kinds of electronic equipment to each other through phone lines and other types of long distance connections (e.g., satellite hookup).

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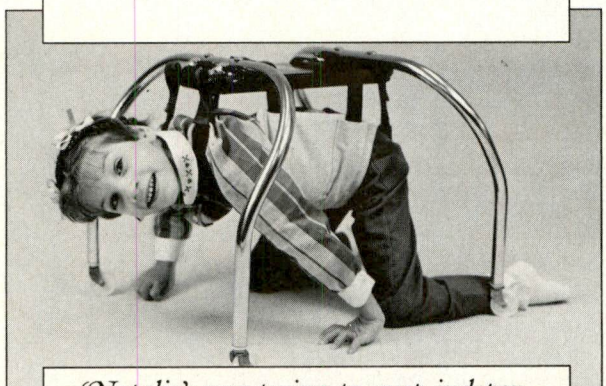

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During an online conference, members can learn about the clever new products offered by a guest speaker's mail order firm, ask about new products under development, or pick up some helpful tips on how to shop for an adaptive device.

sharing of information by those who participate in the CompuServe component of the service. Through the message board, for example, a student can describe his or her experience with a new speech synthesizer, an office worker can ask where to find a good Braille printer, or a parent can read about a new educational software package. Members can complain about the high cost of adaptive equipment, praise a new mail-order company, or share a tip on using an innovative teaching strategy. Members can even form lasting pen-pal relationships with other members who share an interest or a special need.

Through the forum's library of text and program files, special education teachers can obtain descriptive lists of software for their students. Parents can "download" free public domain software for their children to use at home. A visually impaired computer hobbyist can read about IBM's new Screen Reader system that uses a speech synthesizer to speak aloud text that is displayed on the computer screen.

During an online conference, members can learn about the clever new products offered by a guest speaker's mail order firm, ask about new products under development, or pick up some helpful tips on how to shop for an adaptive device.

COMPUSERVE

CompuServe also has many other information services that will probably interest special educators or persons with special needs. Such services include the Education Research Forum, the EPIE Database, the Handicapped Users' Database, the Rehabilitation Database, and the Disabilities Forum. Additionally, there are other discussion forums for users of IBM computer equipment. The IBM New Users Forum, the IBM Communications Forum, the IBM Hardware Forum, and the IBM Software Forum are among them.

In fact, many of the online activities sponsored by the Exchange are coordinated by Georgia Griffith, an information professional who is deaf and blind. By all accounts, Georgia is an expert in computer hardware and software for persons with special needs. In addition to her work on the Exchange, she operates the

Handicapped User's Database on CompuServe. Few of the people with whom Georgia interacts online know that she cannot see or hear. They only know Georgia for her expertise, sensitivity and keen wit.

JOINING THE EXCHANGE

To get started on the IBM/Special Needs Exchange, you must have a computer equipped with a modem and telecommunications software. If you are not already set up to telecommunicate, your local computer store or perhaps a knowledgeable friend, can help you select and install the proper hardware and software.

Next, call or write the IBM/Special Needs Exchange and request the new member information package. In addition to some descriptive literature about the Exchange, the package includes a CompuServe IntroPak and a User Guide to the database of educational software. The CompuServe IntroPak provides you with a temporary personal identification number, a password, and a $15 usage credit so you can log on to Compuserve to explore the Exchange (and other CompuServe services). By the way, there is no cost to join CompuServe, but there is a modest charge for your online time. For most users, the CompuServe network is just a local phone call away.

The User Guide that comes with the information package includes instructions on how to log on to the dial-in database at LINC headquarters and offers tips on how to search the system to find the software information you need.

COSTS OF USING THE EXCHANGE

"No-frill" modems, which are available as internal or external devices, can be purchased for well under $200, with internal modems generally costing less than external. Full-featured external modems from popular manufacturers may cost as much as $400 or $500. However, there is little need to buy such a fancy modem. A "plain vanilla" internal or external modem will work just fine. Modems from mail order firms may be the best buy, though a local store may be able to offer the most help in selecting a modem that is right for the user.

Telecommunications software can be purchased for well under $100. Again, mail order has the best prices, but local stores may be the best source for advice on which program to select. It should be possible to get both a modem and software for about $200, maybe less.

The online cost for using CompuServe via the CompuServe network (which is available in most medium and large metropolitan areas) is based on an hourly fee that ranges from $6 to $15 per hour, depending on the type of modem equipment, plus a $.30 per hour network surcharge. The costs for those who do not have access to a CompuServe network phone line

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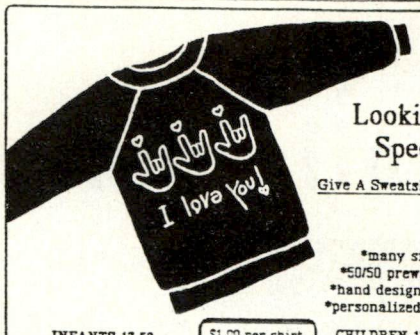

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The cost of using the searchable database set up at LINC headquarters is the cost of the long distance phone call, which will of course vary depending on the user's location. The long distance operator can quote the cost per minute to Columbus, Ohio.

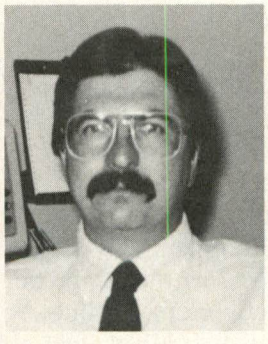
While the costs may seem a bit high to some, it may be helpful to compare the cost, for example, to the cost of attending a conference in another city -- which would be another way for a parent to interact with a large number of parents and educational professionals. Also, because the service is convenient and available 24 hours per day, it is a good value.

SERVICES WITHOUT MODEMS

There are plenty of information references and referral centers ready to serve you. For computer users who do not have a modem, there is the IBM National Support Center for Persons with Disabilities. This major center, also sponsored by IBM as a public service, responds to computer users who phone or write for help. Some of the other information centers that serve persons with special needs who are interested in assistive technologies are described elsewhere in this issue of EXCEPTIONAL PARENT. The folks here at IBM/Special Needs Exchange will be happy to send you a list of these and other information centers that can help you. ♦

For more information about the IBM/Special Needs Exchange, call or write:

IBM/Special Needs Exchange
P.O. Box 434
Pawtucket, R.I. 02862
(401)725-3973



Jack Moore is an information scientist for LINC Resources, Inc. presently working as project manager for the IBM/Special Needs Exchange. He received a bachelor's degree in urban affairs from the University of Maryland. Jack and his wife, Deborah Anderson, live in Pawtucket, R.I.

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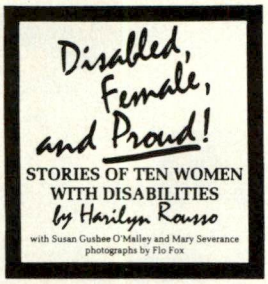

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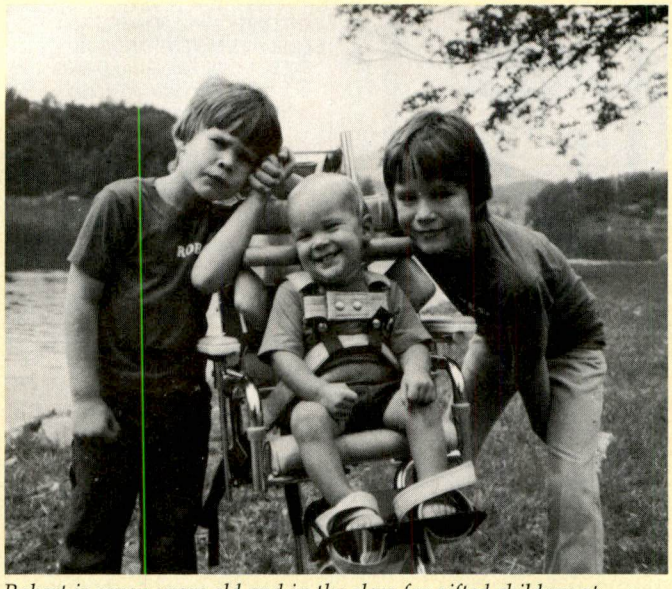
RANDY and ROBERT

by Robert Rutland-Brown



Robert is seven years old and in the class for gifted children at Chisholm Elementary in New Smyrna Beach, Fla. His older brother Wesley is twelve and his younger brother Randy is six. Randy is legally blind and has cerebral palsey.

I have a brother, Randy. He just turned five. My name is Robert. Randy is handicapped, which makes me sad. We still do fun things together. We share a room. Whenever he wakes up, he says "Dirt, up!" (Randy can't pronounce Robert so he calls me "Dirt.")

Randy can only see a little bit. Randy has trouble moving his right hand. He can't walk yet, so he crawls around on the floor. He has a pair of special shoes that might help him learn to walk.

Randy and I play "mommy and baby" together. Whoever is the mommy takes care of the baby, changes his diaper, gives him a drink, and sometimes reads him a book. Another game we play is called the taste game. I give him different kinds of food. If he knows what it is he says the name of the food. If he doesn't know the name of the food, or doesn't like it, he says "Yuck."

Randy has a battery operated car he can drive around in the front yard. The only problem is that he might go in the street or run over the neighbors' plants, so I stay out there and keep an eye on Randy. Randy's a great swimmer. He can swim the width of the pool without a breath. But I'm always scared that he might not know where he is or get tired and drown, so I stay close to him.

I'm sad that Randy's handicapped, but I know there's nothing I can do about it. My friends think Randy's special because other little sisters and brothers are ordinary sisters or brothers. Randy will always be special to me.

Your child can;

IN YOUR CHILD'S ROOM

by D. J. Orr

Some children do not "pick-up" new skills as easily as other children. They often need to review and practice skills before the skill is actually learned.

1. Keep own calendar of school and home events

2. Organize drawers and shoes (may label drawers with color coded labels)

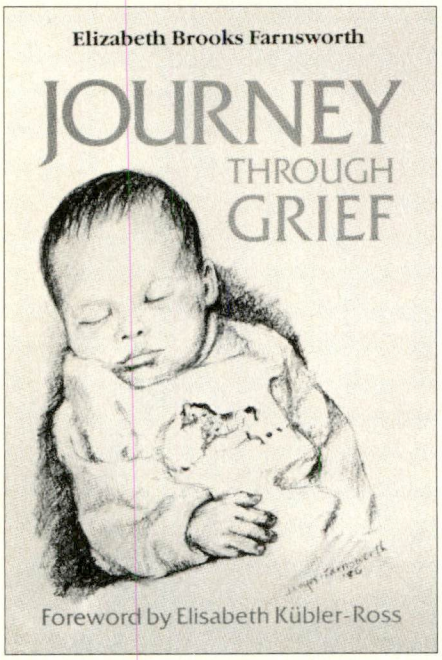
3. Match clothes and pick own clothes to wear

4. Roll matching Socks

5. Set own alarm clock

6. Watch a clock to know when to eat, play, etc.

7. Match shoes



This is the true story of a crisis in our family. Actually, there were two crises -- Thomas' birth and Thomas' death. Thomas had Down syndrome complicated by heart disease. His birth touched off a very real, very painful grief process over the loss of the expected child. Grief is not bad. It is necessary -- necessary to begin a transformation process in which we construct a new identity. In this case, we were challenged to create an identity which included being the parents of a child with a developmental disability. We began to learn the meaning of patience. We also knew frustration. In fury, we learned to love.

When Thomas died at the age of seven months, he died a baby -- a very lovable, cuddly baby. The crisis of his death stripped away our coping skills. It forced us to begin the hard work of adaptation anew. In a heartbeat, we had become a bereaved family. Once again, our emotions took roller-coaster rides. Over time, healing became evident as I charted the journey through grief in a lovely cloth-covered journal given to me by a dear friend, Toni Doan. In suffering, we began to see our strength. We learned to rejoice in the infinite beauty of Nature and the cyclical patterns which usher in rebirth. In the aftermath of intense grief, new values emerged. No, I would never have chosen this way, but I want to survive. Desire to survive is the necessary ingredient for healing to begin.

I believe we can create meaning, meaning which is rich and holistic, if we so choose. The message is: EVEN IN THE WORST OF CIRCUMSTANCES, WE HAVE SOME CHOICES! The choices are difficult. They do not come by chance. Before choices even become evident, we must endure many lonely hours of pain and hurt. The message here is not to pile on additional "shoulds" and "oughts." This story is shared to give hope. It is shared to give permission to grieve. It is also the culmination of a personal goal — to create meaning in Thomas' life just as it was. It is a love story. It is a story about learning to forgive life and moving on.

This excerpt was reprinted with permission from Journey Through Grief *by Elizabeth Brooks Farnsworth. Susan Hunter Publishing, Atlanta, 1988. Readers can purchase copies of the book through the Exceptional Parent Library, see page 61.*

Mrs. Farnsworth has also shared the following story about her family with us.

Our grief began the day our second son, Thomas David Farnsworth, was born--October 13, 1984. My husband, Dave, and I felt prepared and elated about the arrival of our second child, the child who would complete our family. Michael, who was four years old, also seemed excited and ready for the new arrival. Less than one hour after Thomas' speedy, uncomplicated birth, the obstetrician appeared at my bedside and somberly said, "Your baby looks a little funny."

His words cut me to the core, even though, rationally, I knew he didn't intend for the words to be taken literally. Giving birth is an emotional experience, the culmination of months of waiting and preparation. When all is not as expected, a very real grief process is set off. Those in the helping professions need to be aware of this and to be very careful in dealing with parents during this period. We need other people, professionals included, to hold our baby, to show warmth and compassion for each member of the family. We are thrust into crisis; it takes time and support for adaptation to occur. We need to be told that our feelings, ALL of our feelings, are normal.

A week later, the doctor's diagnosis was confirmed--Down syndrome. We were stunned and enraged that this could have happened to us, to our family, to our child. I wept and cursed God, the obstetrician, and anyone else who seemed to be an easy target. I just did not see how this could have happened to us. I didn't know how I could care for a child with special needs. I'd had virtually no experience with persons with disabilities; I had much to learn, much growing up to do. Gently, my kind husband suggested, "We can do it together." As I watched four-year-old Michael respond to his brother, somehow, I, too, came to see that we had, in fact, had a baby, not a label.

As I nursed and changed Thomas, bathed him, and read to both boys together, the pain diminished. Once I realized that we were still very much a family, I began to rise up, to see that we had so much to offer Thomas and that he had a lot to offer us, as well.

A strong believer in bibliotherapy, I ordered books, newsletters, and tapes about children with Down syndrome.

I took nothing for granted with Thomas, and his every accomplishment surprised and delighted me. While Michael had presented expected delights,

Thomas offered a bittersweet challenge. I became involved with other parents of special children, which was very helpful. They demonstrated new coping skills and attitudes. The old excitement I thought I had lost forever began to creep back into my life. Yet, there were days that I backslid. I learned firsthand that no one is perfect. It was as though Thomas gave me permission to accept my own limitations, too.

When I took Thomas to the pediatrician for his two-month checkup, I was dumbfounded and crestfallen that he had not gained weight as a result of my dedicated parenting. Emphatically, I told the pediatrician that something MUST be wrong. He suspected an underlying reason for Thomas' failure to gain weight.

We were accustomed to being able to solve problems by putting forth our best efforts. Having nursed successfully before, I could not understand why my baby wasn't growing. This was a bitter pill for me to swallow. Another chest x-ray revealed the problem. Thomas' heart clearly was enlarged.

A more extensive test, the echo-cardiogram, was done to reveal the specific problem areas in Thomas' heart. Essentially, there were two holes in his heart causing increased blood flow, which explained his failure to gain weight.

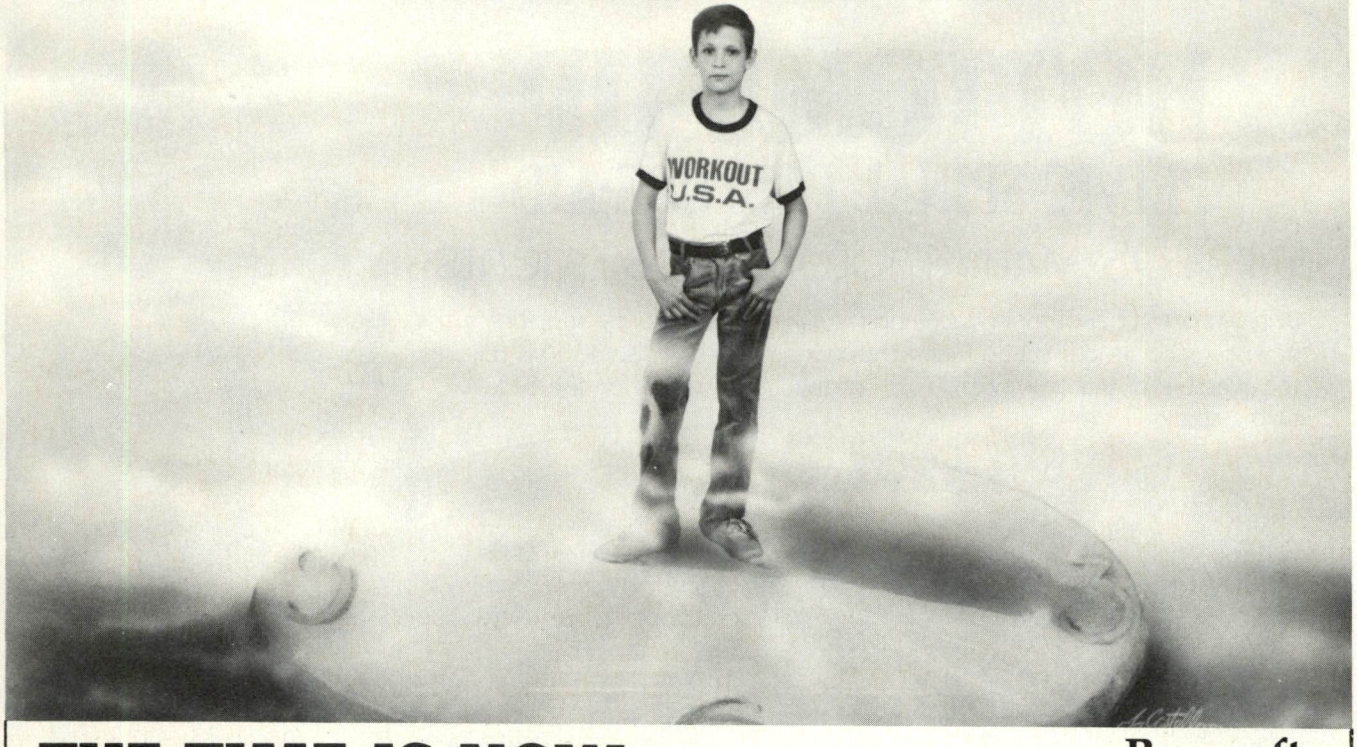
We'd adapted somewhat to the fact that Thomas had Down syndrome; then we were confronted with the reality of a major disease which absolutely required surgery. We went home with medications and new instructions for feeding an infant. The old rules didn't work. Breast-feeding was not enough. Thomas needed extra formula after nursing, as well as high calorie supplements. Again, we grieved. Logically, we knew our parenting wasn't at fault, but emotionally we were facing our limitations head-on.

Life went on. Michael went to nursery school. I stayed at home, trying to keep Thomas away from viruses which could be deadly with his heart disease. Between Christmas and April, Thomas did grow and develop. He'd giggle and coo and bat at objects. He became a full-fledged member of our family. With compassionate, loving support from an early intervention worker, I began to feel warmth and pride over Thomas. He became quite a little charmer.

In April, Thomas underwent open heart surgery. We were ready and optimistic. Hospital life required new coping skills. Everything in our lives was askew. Our family was separated, because I spent time with Thomas so that I could nurse, stimulate, and love him.

We worked together as a family, even though we faced physical separations. When you have no choice, sometimes you surprise yourself with new strengths and attitudes.

Hospital procedures and



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routines were numerous. On good days, I enjoyed meeting new and stimulating people and becoming literate on the details of Thomas' condition. On bad days, the strain wore me down; and I wanted everyone to go away and leave us alone. Separations, worry, rapidly changing conditions, and lack of normalcy and stability change a person.

What I saw and learned in that hospital! Babies who never, ever left those walls. I become angry when someone tells me that such difficulties are "God's will." Surely, God does not plan such things. I saw too much to believe that; yet, I also saw and felt what surely must be the love of God in a greater way than ever before.

There were unexpected gifts. I met many loving, wonderful human beings I never would have met any other way. I learned new ways of coping with stress. I invented my own form of mind control -- I allowed the beauty of nature to envelop me and sustain me. I came to realize that I could not function without respite and that I need comfort and relaxation.

Thomas improved greatly after the surgery, and we thought we were homeward bound. Then, he contracted a virus. His little body fought and fought; but it was the final insult. He had endured so much. Even now, there are days I am flooded with hurt. When a child dies, part of a family's future dies also. I suspect such days will come and go throughout my lifetime. Yet, I do know that he gave his all, and we gave our all.

I believe something new can arise from sorrow. No, the pain doesn't magically vanish, never to appear again. Pain is part of life. All of our lives have pain. There are days that I feel heavy with sadness over Thomas' death; there are days I feel richer than I ever dreamed possible. Thomas taught me new attitudes, to look at the person behind the label, to see that all of us have strengths and that we all respond to love and affirmation.

If we can let go of our anger over the unfairness of life, we can discover the pleasure. A tragic loss occurred. I cannot change that. The only choice I have is how I will respond to this crisis.

With my Compassionate Friends and other special people, I have come to realize that I am not alone. Others hurt. Others learn to rise above the hurt. Others learn to live in a more loving way. Others feel the hurt in each of us and learn to reach out to help. I can too.

I will never be the same. Thomas taught me to be a survivor and to expand my possibilities. I weep for every parent who experiences the death of a child. It is unnatural. It is maddening. None of us would choose to grow in this way, but it is my hope that another lonely, bewildered parent will feel validated in some way by the sharing of my journey through grief. ♦

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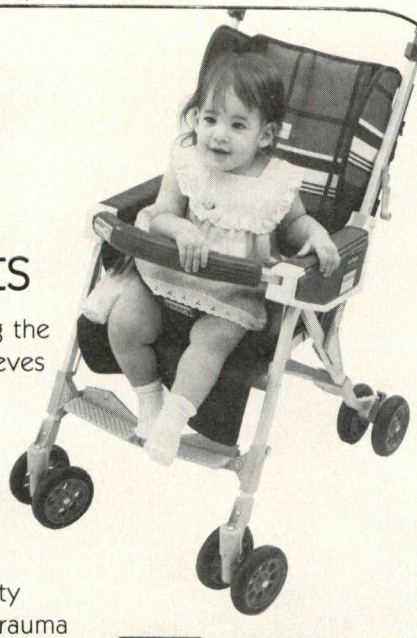

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CONNSENSE '89

The sixth annual conference of the Connecticut Special Education Network for Software Evaluation will be held on July 11-14, 1989, at the University of Connecticut, in Storrs, Conn. Proposals are being sought on a wide range of topics having to do with technology for those with disabilities. We are particularly interested in successful programs and strategies.

Please write for a proposal format. For more information contact: Chauncy N. Rucker, UConn Special Education Center Technology Lab, 249 Glenbrook Road, U-64, Storrs, Conn. 06268, or call (203) 486-4031. The deadline for proposals is November 15, 1988.

NEW PUBLICATIONS ON TECHNOLOGY

Rehabilitation Technology Service Delivery: A Practical Guide, by RESNA, Association for the Advancement of Rehabilitation Technology, is a state-of-the-art resource document on service delivery. The guide was written based on practical experience by rehabilitation-technology service delivery providers.

This guide does not give dogmatic "recipes for success" but instead emphasizes the necessary questions to be addressed in planning, developing and implementing a technology service delivery program, as well as increasing the effectiveness of existing programs. It also includes experience-based "rules of thumb," and a chapter that describes other resources available and where to find them.

Copies of the guide cost $18 and can be obtained by writing RESNA, Suite 700, 1101 Connecticut Ave. N.W., Washington, D.C. 20036 or by calling (202) 857-1199.

Computer Access in Higher Education for Students with Disabilities, by Carl Brown and Colleagues (1987). This reference handbook explains the process of adapting computer technology on the community college campus for students with disabilities. Chapters include creating access and adaptations for students with visual, orthopedic and learning disabilities. Profiles of the center director and successful users are combined with case studies to provide a useful spectrum of examples. A limited number of printed copies are available free from the High Tech Center for the Disabled, California Community Colleges, 1107 Ninth St., Sacramento, Calif. 95914. The text is available on IBM-formatted floppy disk by arrangement with the author.

TECHNOLOGY-RELATED PROGRAMS

The following two programs serve children of different ages and disabilities. They represent unique circumstances and illustrate the excitement that comes when a student is given the right combination of hardware, adaptive equipment and software for learning and communication. Special education technology in these programs is successful because it is used to enhance individual learning, mobility or sensory needs in ways unmatched by other methods. Moreover, once students begin to use technology appropriately, they experience greater independence.

Public/Private Technology Project

The innovative Special Education Technology Center in Fairfax County, Va., is a blossoming initiative of a school district/business sector partnership that has parlayed local know-how into a system-wide resource where the payoffs are educational. Barely one year old, the Technology Center provides individualized student

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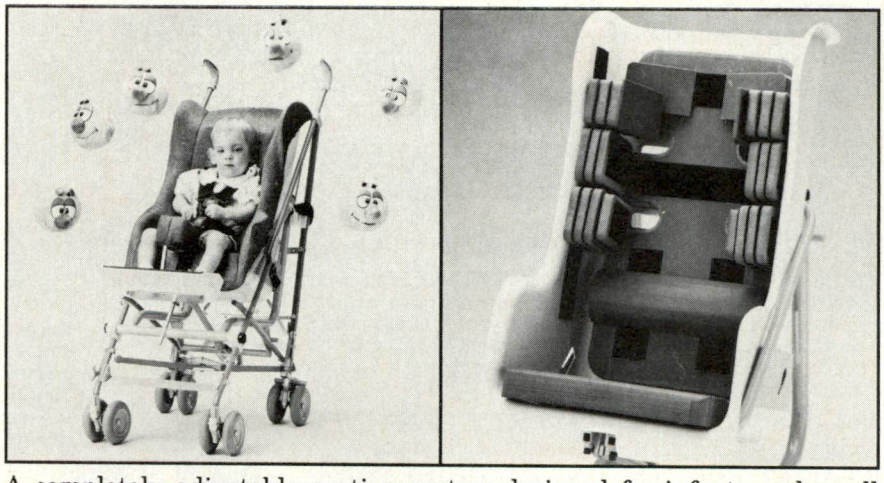

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assessments, equipment and training for youngsters and professional staff.

Thanks to seed money totalling $200,000 given by local businesses and industry to the Fairfax County Public Schools Foundation, special education technology is becoming an integral part of the instructional program for students with disabilities.

Professionals evaluate referrals, prescribe particular devices, train staff and collect computer hardware, adaptive equipment and software that go toward solving specific problems children face in the classroom.

Public funds allocated for special education technology have been supplemented with foundation funds donated by area corporations. The extra monies help to increase the equipment inventory; and as a result, a greater number of students can "borrow" equipment for use at their school.

For example, a bright Fairfax County student who cannot make the physical movements needed to write is no longer dictating to a teacher's aide who would then type the final draft. Outfitted by the center staff with a computer and a single switch that enables him to bypass the keyboard, he now prepares his own work.

Technological Early Intervention Program

The UCLA Intervention Program for Handicapped Children serves students from infancy to five years of age who are born with cerebral palsy, Down syndrome, spina bifida, chromosomal disorders and other birth defects. What is special about this early intervention program is a commitment to appropriate technology use and the production of original software to help children learn.

The technology project aids young, nonverbal readers who cannot use computer equipment such as a standard keyboard. The staff has found that social interaction, play and language have been enhanced through the use of computer software programs.

The computer is the "common denominator or tool" that helps the children reach beyond physical limitations. Students work with computers twice weekly in two small groups: one for children 18 months to three years and another for three- to five-year-olds.

Not yet ready for keyboarding skills, preschoolers use microcomputers adapted with devices that suit individual needs. Some input information using single switches, while others work with nontraditional keyboards that have a touch-sensitive surface. Software designed especially for use with a power pad allows those as young as 18 months to use a microcomputer.

The UCLA Intervention Program's Microcomputer Project

"This book could well be the difference between a mentally retarded person becoming a law abiding citizen . . . [and] a criminal being taken care of by society. The approach is effective, and very human."
--Virginia Satir, Ph.D., One of America's Foremost Family Therapists

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☐ **By Rosalyn Kramer Monat, M.Ed.**

Counselors, educators, administrators, and therapists, relatives and friends, legislators and advocates--everyone concerned with the social-sexual rights of persons with mental retardation--will recognize the extraordinary value of this intensely practical volume. Here is a thoroughly professional, pragmatic guide on sex counseling and sex education for individuals functioning at all levels. Written clearly, with drawings to use in teaching children about sex.

1982, 150 pages, illustrated. Paper, #578207, $20.50.

DOWN SYNDROME:
A Resource Handbook

☐ **Edited by Carol Tingey, Ph.D., F.A.A.M.R., Early Intervention Research Institute, Utah State University**

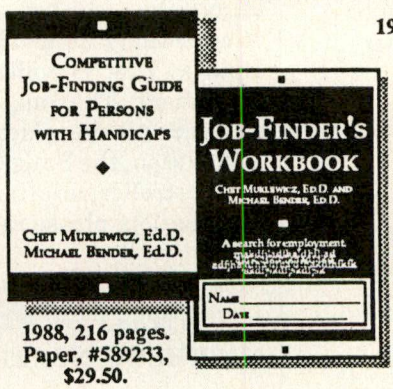
Personal in approach and direct in style, ***Down Syndrome*** is a different approach to Down's. Separate sections focus on these areas: Family; Total Development; Education; and Social needs. This lovely and easy-to-read book gives you a lot of information in a small space. Several chapters are written by parents of children with Down's.

1988, 240 pages. Paper, #845620, $19.50.

COMPETITIVE JOB-FINDING GUIDE FOR PERSONS WITH HANDICAPS

☐ **By Chet Muklewicz, Ed.D., Marywood College, Scranton, Pennsylvania, & Michael Bender, Ed.D., The Kennedy Institute, & The Johns Hopkins School of Medicine**

Lack of competitive job-finding skills keeps many persons with handicaps out of the labor market, despite desire to work. Chet Muklewicz, a career and employment counselor to persons with handicaps, and Michael Bender, a special educator, offer solutions to real problems faced by persons with various handicaps, and present proven strategies for finding and keeping jobs. This book contains easy-to-follow instructions that will help you help your disabled person to find and keep a good job!



1988, 216 pages. Paper, #589233, $29.50.

Also from Muklewicz & Bender:
JOB FINDER'S WORKBOOK

Contains more than 20 helpful forms for the job-seeker. These clear, easy-to-follow forms help clients get and keep good jobs.

1988, 60 pages per workbook. Paper, #589152, $35.00 for set of 10 workbooks. (Sold as set only.)

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has published a beginning booklet for new technology users entitled *High Tech For Me.* It is available for $2. The LAUSD/UCLA Microcomputer Handout that lists technology hardware, software and resources effective for their students is also $2. Software titles, which require the Apple II+, IIe, or IIGS Color Monitor and Echo speech synthesizer, can be purchased for $16 each.

For a listing write: Kit Kehr, UCLA Intervention Program, 1000 Veteran Ave., 23-10 Rehab, Los Angeles, Calif. 90024. Note: Purchase orders cannot be accepted. Checks should be made payable to UCLA Intervention Program.

PUBLIC TRANSIT ACCESS PROJECT

The National Easter Seal Society has been chosen as the administering agency for the Public Transit Access Project, the effort of the Urban Mass Transportation Administration (UMTA) to improve access for people with disabilities.

The Public Transit Access Project is designed to meet the increasing need for accessible public transportation for people with disabilities. Representatives of the transit industry, organizations of public transit operators and people with disabilities will cooperate in developing a model program for use across the nation.

The model program will first be implemented in as many as six demonstration sites, coordinated by local transit agencies and disability organizations such as Easter Seals and independent-living centers. This action by UMTA was the result of a mandate from Congress to find ways to better accommodate the transportation needs of people with disabilities.

For information contact the National Easter Seal Society, 2023 West Ogden Ave., Chicago, Ill. 60612, (312)243-8400.

COMPUTER LEARNING MONTH

October is Computer Learning Month (CLM), a public service/public education campaign that promotes computer literacy and the benefits of technology.

To support these objectives, CLM and its sponsors will produce a variety of materials for several different audiences. For parents and families, CLM will distribute a Family Activities Guide, which contains dozens of activities for learning, sharing and having fun with computers, and a book, *Preparing for a Career in the 21st Century*, which will focus on ways computers are used in different vocations. In addition, CLM will produce another book, *Everything You Need to Know (but were afraid to ask your kids) About Computer Learning*, designed to help parents learn about the value of computers as educational tools.

For more information on CLM '88, write to: Computer Learning Month, P.O. Box 60007, Palo Alto, Calif. 94306-0967.

NEW COMPUTER ACCESSIBILITY LAW

Section 508 of Public Law 99-506, the Rehabilitation Act Amendments of 1986, goes into effect this month and requires that the federal government purchase electronic office equipment that is usable by people with disabilities.

While this act may seem to have a limited scope, all people with disabilities will ultimately benefit from the workplace initiative.

Since the federal government is the largest buyer of electronic office equipment and the primary market for many computer companies, the industry can be expected to begin making their product lines more accessible to people with disabilities rather than risk losing the business of one of their largest customers.

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"Jim and I have different ways of handling money."

Family styles of managing money

"The argument began when our thirteen-year-old son, Ricky, announced to my husband and I that he was not going to attend the Queens School this fall." Mrs. Quinn, a dark-haired woman in her mid-forties spoke quietly and tearfully. "Ricky thought that our family could not afford to send him to private school because we had already spent a great deal of money to help him. Besides, he wanted to return to the public junior high school with his old friends from the neighborhood.

"Ricky has been the only member of our family who has always been willing to talk about money. In the spring, my husband, Jim, had a big fight with Ricky when he wanted to have a newspaper route. Jim told him to demonstrate some responsibility in his school work before taking on anything else. Ricky told Jim that he punished him all the time by not giving him bus allowance. Ricky wanted to be free of that.

"Jim was out of control. He came as close to hitting Ricky as he ever had.

"First, Jim tried to explain to Ricky that we had had a serious discussion about the kind of school he needed. He explained that we didn't think Ricky could get the kind of education that would be most helpful to him in our local junior high school. He wouldn't get the individual help and small classes in the public school.

"At the time, Jim never asked me what I thought. Ricky began to tell Jim that nobody knew what we could afford and that everybody felt there were other important things that weren't getting done because of the private school tuition.

I am ashamed to bring friends home.

"Ricky then raised the thorny issue that my daughters, Jeannie, who is fifteen, and Priscilla, who is eighteen, and I have tried to speak to Jim about -- our house. We haven't really done anything for our house for over a decade. Everything seems to be in disrepair. Almost everything we have is old or fading. The furniture is collapsing. Repairs go undone because Jim says he'll get around to them. He doesn't believe it, but my daughters and I are ashamed to bring friends home.

"This time Jim actually slapped Ricky. I know how upset he must have been because it is the first time he has ever hit any of our children. Ricky ran off to his room crying. Then Jim and I began an argument that still hasn't ended. He blames me for the children's attitude. He thinks nobody appreciates him. He's wrong. The kids love him and are worried because he works so hard. He always tells us that we've never lacked for anything and that we'll get through. He says that the children get their ideas about lack of money from me -- that's probably true.

"Jim and I have different ways of handling money. We had both saved a good bit of money before we got married, and I continued to work until Priscilla was born. In those days, we were living in a small apartment.

"When I became pregnant with Jeannie we both agreed that it was time to get a house. I think the money thing started back then. We had different views on what kind of a house to get. I wanted a house with a back yard and space. I recall that Jim only seemed to be interested in a place to live that didn't require a lot of upkeep. After

looking around, we finally settled on a large four-bedroom house that was run down. I had hoped that over the years we could fix it up and really have something very nice. It's almost happened, but not quite.

"When Ricky was born our expenses increased. At about the same time, Jim got a job promotion, but it took much more of his time and energy. There's no question that Jim works very hard. He's exhausted at the end of the day. And so, he has had less time and energy to do the kind of fixing up that would get things going or we could afford. Now I think the fixing-up is a necessity not an option. To a certain extent, that's where the issue of money comes in.

"I was brought up to keep careful track of money and try to budget everything; Jim was not. So I'm never sure exactly how much money we have or what we can really do. Each fall we start with Jim telling me that we're going to have to be very careful this year because taxes and repairs are going up and he's not sure how well his sales will be this year. So I'm always a little scared and careful about my budget. Then, all of a sudden, I find that Jim's bought things for the house, the children and me. And I always feel very troubled by that. I think he expects us to be very excited about his purchases, but he doesn't understand how we feel. I can't get angry with him for doing something for us, but he never asks us what we really need or want. He buys what he feels we need. That's the way he was brought up. Jim's father is a nice guy, but not dependable. He's either throwing money around or barely making ends meet. Jim and his brothers always had to bring money home to his mother -- he still does.

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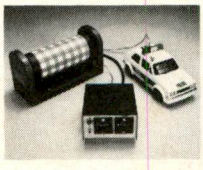

A basic Active Stimulation System including Barrel Switch, Programmer and Battery Operated Toy.

"I'm working part time as a secretary. I waited until last year when Ricky started junior high. When we start to argue about money Jim says that if I wanted more, I could work more. I know I could help him with his accounts -- I'm a better bookkeeper than the one he has now. I'd do a better job than she does. If I mention it, he says he doesn't want my nose in his business. I always find that very insulting.

"I told him that the children think our marriage is in terrible shape. I'm beginning to agree with them. I think this all finally reached him when my daughter heard our argument and came in the room to tell him it was time to treat me better. That's what brought us here."

"To tell you the truth, I'm bewildered by all of this." Mr. Quinn, a tall, slender man in his late forties looked very tired and spoke with a sense of despair. "Louise and I have a good marriage. At least I think we have the same values and the same expectations of life.

"We've always considered the children first when taking vacations and buying things. We talk about things we need and would like to have. But it never fails, when I come home with something new for the house -- like the VCR I bought two weeks ago -- she screams and shouts that I never discussed it with her. I thought we had. This happens over and over again.

"I discussed Ricky's private school expenses with Louise in great detail. I made it clear that we could afford the tuition.

"Louise gets a lot of her attitudes about money from her father and sister. Her father made his daughters account for every penny they spent. He used money as a weapon. If they wanted something, he would make them do something that he wanted.

"When Louise wanted to go to college, she wanted to study art. Since he wanted her to be practical and be a school teacher, he wouldn't give her any money unless she took the education courses. She taught school for several years before and after we were married. She never really liked it -- and even now she is discussing some other career. I have made it clear from the beginning that I would help her change careers and that she should do something that she enjoys.

I have worked hard to take care of everyone. Sometimes I think nobody cares -- neither Louise nor my kids. And Louise is right. I think she eggs them on about me. I have helped her more than she appreciates.

Everybody seems to be mad at me.

"Her father has been very sick the last four years. I know how worried she is. She has spent a lot of time and money going to see her parents. I have rarely complained and have been supportive of the kids. I watch them at school plays and sports and go to PTA meetings. I think her family takes advantage of her. If I mention it, she doesn't talk to me for a day or two.

"I'm in the insurance business. It's very difficult for me to predict what I'm going to make each year. So I always try to be cautious, because some years are good and

some are bad. Toward the end of the year, I can tally my commissions. There's nothing in this world that I like more than my wife and my family. Right now everybody seems to be mad at me about the money, and I don't know what to do."

Mr. and Mrs. Quinn came to discuss a dispute between them that centered around their son attending private school. The dispute began when Ricky Quinn did not want to add to the family's financial burden by attending the school and asked to go to his public junior high school. In fact, the management of the finances was a long-standing problem for the family. Mrs. Quinn thought her husband was selfish and irresponsible about money. She felt that he never consulted her about the family's financial priorities and was afraid to discuss any of these matters with him. She was afraid he would attack her as well as afraid that she would offend him.

Mr. Quinn felt misunderstood and unappreciated. He thought that he had continually discussed the family financial situation and how he was spending the money with his wife. He also felt that over a period of several years she had become less and less supportive of him. He thought that his wife's involvement with the illness of her father, and the responsibility that she had to take as a result, had made her less available to deal with the everyday problems of their family. At the same time, he felt he could not count on her to deal with difficult matters.

Mrs. Quinn felt that her husband was incapable of change and was not sure how much longer she could adapt to the way he lived and worked. Mr. Quinn felt bewildered and attacked.

Each family develops their style of managing money. When two people marry, they bring their different family attitudes about money with them. A major task during the first stage of a marriage is to adjust each partner's style to fit into their new life together.

Mrs. Quinn's family was reasonably affluent. Her father earned more than enough money to manage the everyday living expenses and provide for leisure and recreational activities. He was very orderly and expected his wife and his children to keep systematic records of the money they spent. Although he could be generous, he would refuse to finance his childrens' activities if they did not follow his advice.

Mr. Quinn's family's finances were much less predictable. His father was a salesman who lost many jobs. Because he worked on commission, it was never clear until the end of the year how much money Mr. Quinn's father would earn. Mr. Quinn felt that his father was very generous with the money that he did have, and although Mr. Quinn could be disappointed when his father's income fell short, he felt that his family was a very close one. Because of his father's financial difficulties, Mr. Quinn and his brothers began working part-time jobs early in their lives. Mr. Quinn felt that he had not been able to go with his friends to parties or on trips because of this responsibility.

He was very pleased with the amount of money he was earning when he got married and felt that he would never have to subject his own wife and children to such financial restrictions. Because of her orderly presentation of the information, Mr. Quinn was delighted when his wife took over the management of the family expenses. She felt pleased at that time because he gave her great latitude and responsibility about making financial decisions, even though they were never fully discussed.

The changing stages of family life bring different financial

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demands. Whatever money management style a family develops early is the one they ordinarily turn to, but the nature of decisions may have to change. After the Quinns' third child, Ricky, was born, they were faced with considerable extra expense for his medical care during the first four years of his life. Although some of this was covered by their medical insurance, a good bit was not. As he entered school, these expenses continued for various remedial programs. The crisis came when Ricky refused to attend the private school because of its expense.

Money had always had special meaning to both Mr. and Mrs. Quinn. The extra demands on the family finances because of Ricky worried both of them. Mr. Quinn began to fear that he was going to place his own family in the same position in which his father had placed him. Initially, he was unable to tell his wife how frightened he was. He also had gone into a business, like his father, where he was never sure how much money he would have to spend.

Although each year he had mentioned his concerns about meeting their financial obligations to his wife, he had not understood that, in her eyes, this had not been a full discussion. Whenever she asked questions about expenditures that were made or not made, he interpreted this as a demonstration of her lack of trust.

Mrs. Quinn found her own style of dealing with financial matters completely undermined. She felt her husband did not discuss finances with her. In addition, he had taken away her once regular responsibility for paying the bills. She always felt that he was saying there was not enough money. From time to time he would even tell her that some bills could be paid and others could not be paid. But she would face his anger when she questioned him about their ability to pay bills.

Children learn about their family's attitude towards money and its meaning over many years, even when such attitudes are not discussed. The Quinn children were aware of their father's concern and their mother's distress. They recognized that their father was a very generous man and that he tried to give them whatever they wanted. But as the children got older, especially as the older daughters became teenagers, they wanted to have a greater say as to how money was spent. They also understood that criticizing their father's gifts hurt the father they loved.

Each family has someone who speaks for the family's concerns. In this case, Ricky was the one who felt the most comfortable talking about the family's financial concerns. This was especially difficult for Mr. Quinn, who felt that he had never been able to ask his father for very

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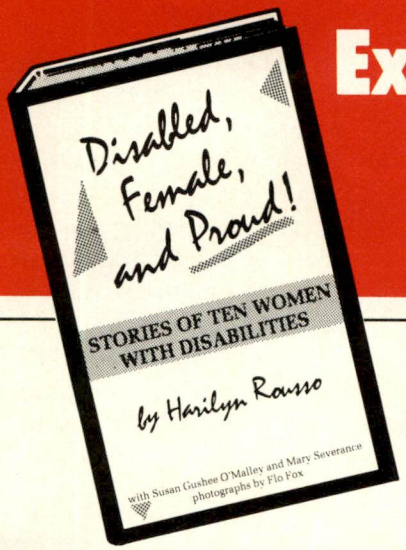


NEW!

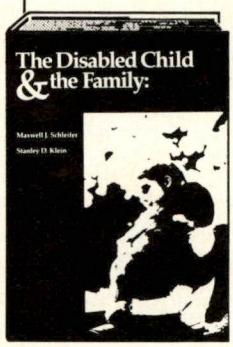
Exceptional Parent Press proudly announces the publication of **Disabled, Female, and Proud!**: *Stories of Ten Women With Disabilities* by Harilyn Rousso with Susan Gushee O'Malley and Mary Severance.

This book offers young women with disabilities empowering role models and the powerful message that they do not have to be or become any one thing because they are disabled and female--they have full lives ahead of them. It offers parents and educators a unique way to help young people learn that making choices--about school, work, family, and love--is what being disabled, female, and proud is all about.

"You do not have to be or become any one thing because you are a woman or because you have a disability. There are a range of possibilities from which you can choose."
-Harilyn Rousso

"Don't overstate your disability and don't ignore it. Be assertive. Figure out what you want and don't let people who say you can't get there convince you that you can't do it. Keep fighting, keep using your head, keep finding as many avenues toward where you want to go as you can."
-Adrienne Asch

"Value yourself, and realize your worth, and realize you're a person too. You have a lot to offer, so offer it. Go for it!"
-Linda Young



"The Disabled Child & The Family seems ideally suited to the needs of parents and professionals alike. It offers a balanced examination of legitimate concerns for both these groups and poignantly emphasizes understanding the child as a whole individual rather than as a symptom or a disability.

This book vividly illustrates that mutual respect for everyone's knowledge and experience--parents' and professionals'--can open the way for children with disabilities to reach their full potential."

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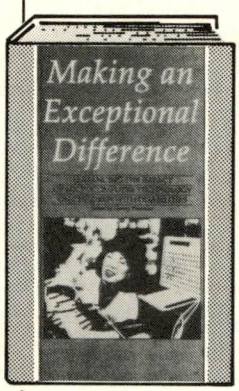
-Rehabilitation Literature



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much. As a result, he interpreted his own son's refusal of the money for private school as a very special rejection.

During the course of several meetings about the current crisis, the Quinns recognized how they had systematically misunderstood each other's perspectives. These meetings presented the first opportunity for Mr. and Mrs. Quinn to tell each other how upset and worried each thought the other one was about their financial situation. Each perceived the other's efforts to help as a rebuff. Mr. Quinn felt that by avoiding the topic of money and by giving Mrs. Quinn gifts for the house or herself, he took care of her concerns. Mrs. Quinn wanted to help her husband more than he was allowing her to help him. She recognized the pressures that he was under and was very disappointed when he responded angrily to her offers of help.

Concern about money matters can obscure the concerns that husbands and wives have about their relationship and the way that their marriage has developed. Mr. and Mrs. Quinn met weekly for a six-month period. First they discussed their concerns about each other and the ways they had failed to communicate these concerns. Then they were able to go back to their joint commitments to their children, to each other, and to their own families.

Mr. and Mrs. Quinn began to have regular meetings with their children to discuss the family money matters and to hear from the children about their own concerns.

Ricky Quinn decided to continue at private school. He had a successful year and planned to continue the next year. Mr. Quinn let him begin a newspaper route. Although over the course of the year Ricky had some of the problems with responsibility his father had worried about, he was able to succeed at both his newspaper route and his school work.

As the weekly meetings became monthly meetings, Mr. and Mrs. Quinn began to discuss their future together, especially when their children would be adults. Finally, they were able to develop a financial plan for when they might retire.

- M.J.S. -

This case has been selected from private practice consultation files. The names and circumstances have been changed to preserve confidentiality.

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Pearl Buck Center in scenic Eugene, Ore., offers training for TMR students including multiple handicapped hard-to-place children ages 6-21. Foster homes are available. Individualized education plans provide consistent training in communication, self-help, functional academics, motor and vocational areas. Call or write **Pearl Buck Center, 5100 W. Amazon Drive, Eugene, Ore. 97405. (503) 345-8506. Director Elisabeth Waechter.**

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Sincerely,

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Unsolicited Letter on File

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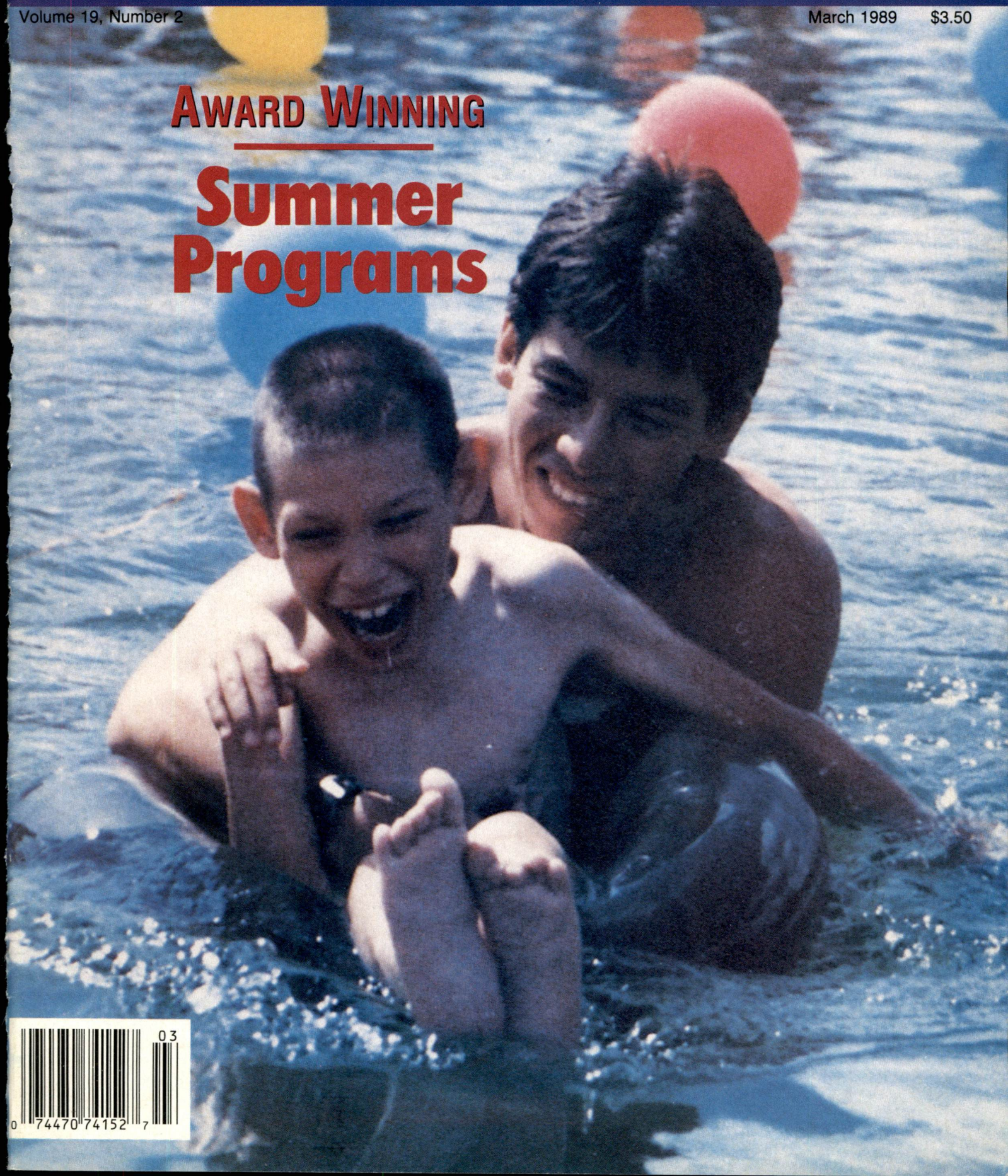

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EDITORS' DESK

Now that the national and local elections are over, the political process can begin. Parents and professionals involved in the lives of individuals with disabilities must continue to work to ensure that existing legislation be fully implemented in every part of our country. We must also strive to pass important legislation that has been proposed and is now being reviewed by Congress. Our editorial for this issue is an Open Letter to President Bush asking him to provide the leadership necessary to meet the commitments he made during the campaign.

We continue to be impressed by the progress being made in so many areas of the lives of children with disabilities. In this issue we are presenting our Annual Summer Program awards. When we gave our first awards over a decade ago, we could not have dreamed of how rich and creative camp programs would become.

The four winners are: Timber Trails, in Tolland, Mass., a program that mainstreams girls with disabilities in a Girl Scout camp; the HASC Summer Program in Parksville, N.Y., for involving brothers and sisters of children with disabilities in a camp program; the Children's Association for Maximum Potential (C.A.M.P.), in San Antonio, Texas, for including a wide range of volunteers to serve children with many different kinds of disabilities including serious medical conditions; and New Horizons in Santa Ana, Calif., for programming for people of a wide range of ages on a year-round basis.

As part of our own emphasis on recreational and leisure time activities, this issue includes an article by Stuart Schleien on how to make sure that the recreational programs being provided are helping children learn skills that will provide a lifetime of opportunities. Kate McAnaney's article on camping illustrates how the support of parents can help make it possible for children with disabilities to attend outdoor programs where they might otherwise be excluded. This month's Family Life discusses a family that must make decisions for all of their children in regard to summer planning. And finally, Robert Bond's article shows how to develop a swimming program.

MORE CONTESTS

The innovative work of so many parents and professionals seldom gets any recognition. We plan to address this problem with two new award programs. The first, the School Mainstreaming Award, is for the best mainstreaming programs at the pre-school, grade school and high school levels. Because technology and assistive devices can change the life of a child and a family, the second contest is for the best description by parents of the contribution of such technology on expanding the opportunities available for their child. Anyone can nominate a program. Both will require a 1500-word description with photographs, if possible.

THANKS

We want to thank the nearly 3,000 readers who responded to the respite care survey. The first report on the results of this study will be presented in our May/June issue.

—M.J.S. & S.D.K.—

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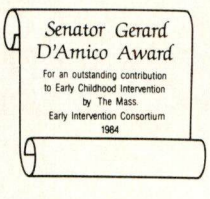

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EXCEPTIONAL PARENT®

Parenting your child with a disability

Recreation

Volume 19, Number 2

MARCH 1989

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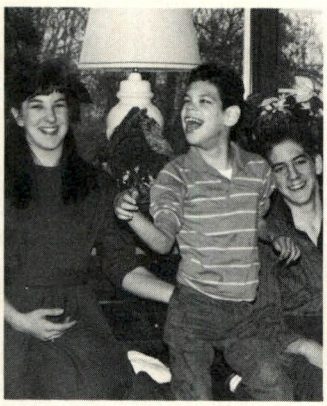

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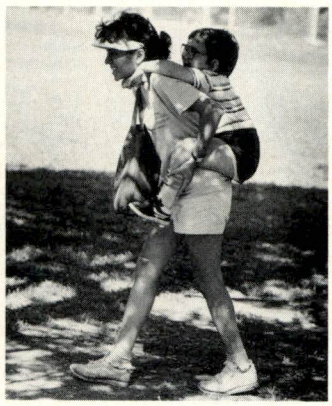

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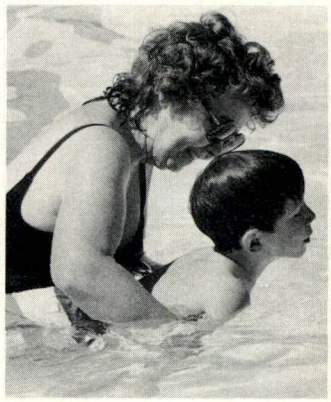

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Cover photo courtesy of Children's Association for Maximum Potential (C.A.M.P.), featured on page 22.

LETTERS TO THE EDITORS

We welcome all contributions to Letters to the Editors. Please send your questions, ideas and responses to:

Letters to the Editors,
EXCEPTIONAL PARENT,
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MORE INSIGHTS FROM ZEPPY

I was moved in reading "Insights from Zeppy: A Father's Essay" by Sal Biondello (July-August 1988), who brings to light a wisdom too often submerged in our competitive, get-ahead world of high technology and high achieve-ment — namely, that every human being, regardless of ability and accomplishment, possesses inherent dignity and is of immeasurable worth.

That belief does not in any way release us from the great responsibility of ensuring that there is ample opportunity for individuals with disabilities to achieve their fullest potential. But it does remind us that in addition to the value of "doing" there is a value in "being" and in our being, each and every one of us, with disabilities and without, has a unique contribution to make. We must not, however, be fooled into thinking that "contribution" can only be measured by the conventional indicators of success, e.g., academic honors, high salaries and the like.

As Mr. Biondello puts so well, "if we, as a species, are to survive, it will be through a fundamental change in what we find important in life." I agree with him and thank him for sharing that insight. It is one that bears repeating.

Diane Barounis
Niles, Ill.

KUDOS FOR EP & ANN LANDERS

Thanks for publishing a magazine that has in print that it's okay to have good and bad days, and awful thoughts, and to allow times when coping is extremely hard!

Although the November/December 1988 issue is only my third, I've seen in all three issues the acceptability for not being 100 per cent up and positive when parenting a child with a disability. I know there are times when it's hard to be a mother to my "normal" son and that doesn't bother me; it's the bad days when it's very difficult to be a mother to my moderately mentally-disabled four-year-old that makes me feel guilty. Your magazine has let me see that other parents and professionals recognize the disappointment, depressions, bad moods, etc. and that those feelings are okay and a part of life with a child with a disability, and thus to not feel guilty!

A thanks, too, goes to Ann Landers for recommending EXCEPTIONAL PARENT as an excellent gift to the new mother of a baby with a disability. I was unaware your magazine existed until written about in her column.

Dorothy C. Michalak
Schererville, Ind.

JOURNEY THROUGH GRIEF

The excerpt from the book "Journey Through Grief," from the bookshelf (October 1988), touched me more than anything I have ever read. It was so close to my own story that I could have written it myself!

At eight weeks of age, my son, Michael, was diagnosed with Werdnig-Hoffman's Disease, which is an infantile spinal muscular atrophy. I read everything that I possibly could on the subject and took him without a second thought for physical therapy. I never let his disability get in the way. He was the happiest, most enjoyable baby I had ever seen and he brought me more joy than I could ever express.

At six months of age, Michael was rushed to the hospital with double pneumonia. He fought and struggled for three weeks and finally died in his sleep the night before he was to return home and the night before Christmas eve. The pain was unbearable yet the joy of seeing him free from tubes and wires was a relief. Having such opposing emotions ripped me apart.

I've never felt so much hurt, sorrow and stabbing pain in my life. I thought I would never be able to go on. It was truly refreshing to read Elizabeth Farnworth's story. She suffered like I did and survived. It meant so much to me to hear her say that "a tragic loss occurred. I cannot change that. The only choice I have is how I will respond to the crisis." Like Elizabeth, "I will never be the same," but I will survive! Thanks so much for sharing this story.

Robyn Roesser
Davie, Fla.

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CORRECTIONS: ADVOCACY SERVICES IN NEW YORK

This letter is in reference to your November/December 1988 EXCEPTIONAL PARENT, in which you have incorrectly listed our office as the referral for protection and advocacy services in New York State in your Resource Section.

The Office of Advocate for the Disabled does provide information and referral services to New York State residents through a toll-free number (800-522-4369). As an executive-level office, staff work with other agencies and organizations on a state, regional and local level but are restrained by law from practicing case advocacy.

The agency that provides protection and advocacy services in New York State is the NYS Commission on Quality of Care for the Mentally Disabled, Bureau of Protection and Advocacy, Suite 1002, 99 Washington Avenue, Albany, N.Y. 12210, (518) 473-7378 (voice only) or (518) 473-7871 (TTD).

V. Paul Smith, Deputy Advocate, New York State Office of Advocate for the Disabled, Albany, N.Y.

FUTURE FINANCIAL PLANNING

I was pleased to see my article on estate planning published in the November 1988 issue. My article included two legal citations to enable readers to refer to additional information on the subject. The reference to the article written by Darcy Chamberlain was mistakenly printed as appearing in the July 1987 issue of the Illinois Law Review. The correction publication is the Illinois Bar Journal. Readers who are interested in reading this or the Carol Mooney article can obtain copies from the nearest law library or request a copy through the inter-library loan department of their local public library. It is unlikely that a public library will have the legal journals as part of their collection.

It's been gratifying to receive phone calls from several of your readers asking for more information. As the parent of an adult with a disability, I know how critical this information is for families. I want to share with your readers what I have told the individuals who have called me. I offer a 2-3 hour inservice presentation on the subject of "Estate Planning for Families with Disabled Dependents."

As part of my commitment to educating parents about areas of interest and concern, I frequently volunteer my inservice time to parent support groups and advocacy agencies. If an agency or support group is interested in my presentation, they can contact me at the law firm of Whitted & Spain, One North LaSalle Street, Chicago, Ill. 60602, (312) 372-7901.

Theresa M. Varnet
Homewood, Ill.

Continued on page 67

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EXCEPTIONAL PARENT will publish letters from subscribers searching for parents with similar experiences, information about specific problems, and resource information. Subscribers may publish one letter a year in Parents Search. Anyone who wishes to submit or reply to a letter in Parents Search should write to:

Parents Search/Parents Respond
EXCEPTIONAL PARENT,
1170 Commonwealth Ave., 3rd Floor,
Boston, Mass. 02134.

*Please indicate whether it is a **search** or **response** letter and in which issue the letter was printed when addressing a reply. All reponses will be forwarded and may be published in our Parents Respond column.*

NOONAN'S SYNDROME

I'm looking for people with Noonan's syndrome. I feel like I'm the only one with the disease. Please help me! I'm 34 years old, but age does not matter. However, I'd like to write to people 12 and over.

R.J.
Massachusetts

TRACHEALESOPHAGEAL FISTULA & ATRESIA

Our two-and-one-half-year-old girl was born with a tracheal-esophageal fistula and esophageal atresia, which were corrected surgically. Because of these and other problems, she did not learn to eat orally until she was one year old.

For more than a year, she thrived on strained food, but could not progress to junior food without vomiting. Then she began to vomit even the strained food, and x-ray studies showed a narrowing of the esophagus, possibly as a result of scar tissue from the original surgery.

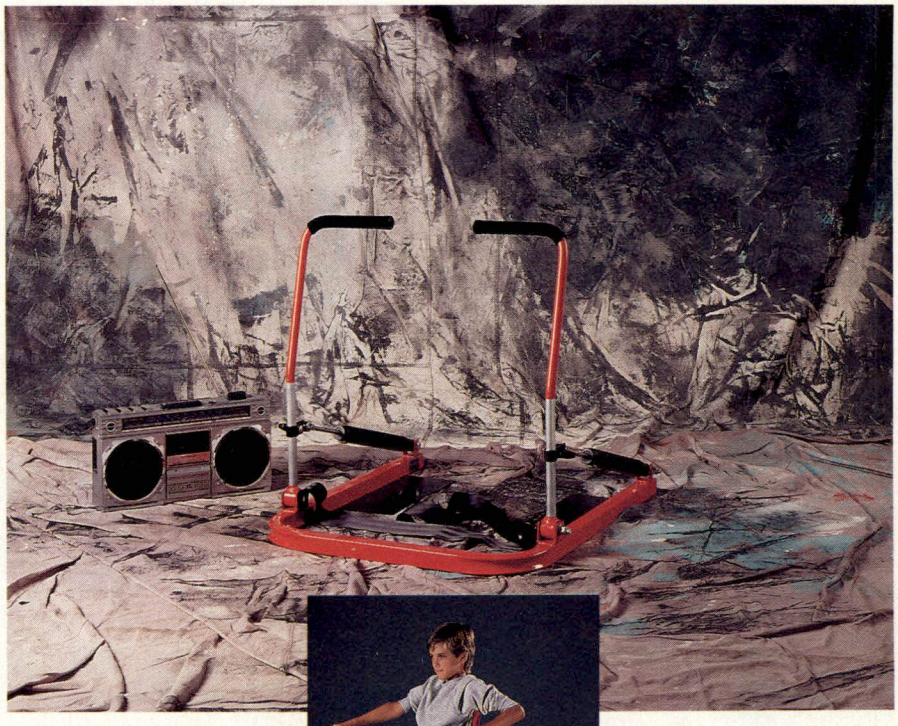
At this time, she can tolerate only liquids orally. Supplemental feedings through her gastrostomy have been resumed.

I would appreciate exchanging information with other families who have children with similar problems.

L.A.
New Jersey

RING 15 CHROMOSOME SYNDROME

Our child, Samuel, is five and a half. Three years ago, he was diagnosed with Ring 15 Chromosome syndrome. He weighed four pounds, four ounces, full term (a caesarean delivery because of breech positioning). He had club feet, bilateral dislocated hips, undescended testicles, hyper-extended knees



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and a mild degree of hypospadias. Some of the other physical characteristics typical of this syndrome which he exhibits are poor muscle tone, curvature and weakness of his index fingers, cafe au lait spots, microretrognathia and a triangular facial shape.

Developmentally, he's experienced delays in several areas — walking at two and a half after surgical correction of his feet and hips, and numerous casts and braces; just this past year managing scissors and a modified tripod grasp on a pencil, etc. He tests out at low normal for his receptive language, but his expressive language lags by at least two years. We used sign language with him, as well as a form of cued speech, and saw dramatic results — and he has been very quick to drop the signs as he acquired each word or approximation.

His speech is quite telegraphic, and he has difficulty with sequencing as well as sound production. Nonetheless, he's currently trying (on his own) to master a knock-knock joke or two.

Samuel is an active, funny child who charms anyone who spends more than a moment with him. He's very tiny still — nearly 39 inches tall and 33 pounds, but growing at a steady rate.

We'd be interested in hearing from anyone who has a child with this syndrome, or a deletion of the long arm of the fifteenth chromosome, or any ring chromosome. It's likely that he will require repeat surgery on at least one foot, so we'd be helped by knowing what others' experience with club feet after initial treatment has been given.

And finally, parents who are dealing with a similarly large gap between what their child understands, and is able to say, might have experiences to share with us.

H.R.
Tennessee

TETRASOMY 18 PT.

I would like to express to you my thanks for this magazine and the quality in which it is written. I highly recommend it to the families I come in contact with who have a family member with a disability. EXCEPTIONAL PARENT helps bridge the gaps of isolation and loneliness.

I have a 24-month-old son who has been diagnosed with an extremely rare chromosomal abnormality, Tetrasomy 18 pt. When he was diagnosed in 1986 there were only 20 cases documented in the world. Information is hard to find and a prognosis is sketchy at best.

Brandon was born with heart problems, hydronephrosis, apnea spells and low muscle tone. He dehydrates very fast and is prone to respiratory infections, thus we spend a lot of time in the hospital. Since his surgery (for the hydronephrosis) he has been doing better but is very delayed developmentally.

Brandon is definitely a diamond in the rough and he has a sparkling personality, but I feel very shaky having no idea what the future holds (or even a hint of it). I would love to hear from some parents with a child who has the same or like disability. Perhaps we can help each other. Thank you so very much. Keep up the excellent work!

L.B.
Nevada

MONODACTLY

My four-month-old daughter, Hope, was born with a form of monodactly. She is missing four fingers on each hand and four toes on each foot. She is also lacking the exterior bone in each arm.

I am a first-time mom who would like to hear from anyone who has experienced a similar disorder.

J.F.
Iowa

Dear Mr. President,

During your campaign, you demonstrated a keen awareness of the issues confronting children and adults with disabilities and their families.

In your statement as a candidate published in October's EXCEPTIONAL PARENT you wrote that "without aggressive public and private support, people with disabilities will not be able to achieve their highest priority, namely the independence necessary to achieve control over their own lives and integration into the mainstream of American life."

You also noted that "we must include people with disabilities and their parents in the process (of providing meaningful access to all aspects of society) to ensure that their real needs are addressed." Further, you pledged to "expand the number of persons with disabilities and parents of persons with disabilities to key positions in my administration."

You made it clear that these are not radical goals. In the campaign you directly addressed the concerns of people with disabilities in your acceptance speech at the Republican National Convention and during the second Presidential debate. You demonstrated that you are willing to remind all of our citizens that meeting the needs of everyone with disabilities is an important part of our national agenda. After the election, you continued to demonstrate your personal interest and concern when you spoke at Gallaudet College using a sign language interpreter and when you appointed a committee to assure access to the Inaugural events for all Americans.

Now, as President, you can provide dynamic leadership needed to move our country towards the goals you support.

Since 1975, the Federal government has played a significant role in dramatically improving the lives of children and adults with disabilities and their families. The Education of All Handicapped Children Act (P.L. 94-142) has revolutionized the opportunities for youngsters to grow to become self-sufficient adults. Today, after more than a decade of implementation of that law, children and young adults with disabilities are involved at all levels of the educational systems. The benefits of educational programs for children with disabilities and their families are now being extended to the preschool years.

At the other end of the educational spectrum, Federal leadership has also encouraged the growth of programs that help youngsters make the transition from school to the adult world of work.

Last year, important new legislation — the Technology Related Assistance for Individuals with Disabilities Law of 1988 (P.L. 100-1407) — was passed and will be implemented in the current year. This law can enable individuals of all ages with disabilities to function more independently through the provision of assistance, technology, devices, and services.

Federal legislation (P.L. 99-506), passed in 1986, ensures technological access for all persons with disabilities to computers and other electronic office equipment in places of Federal employment. This program can serve as a model for employers in the private sector.

Two important pieces of legislation that need to be acted upon by the Congress already have considerable bipartisan support. The "Medicaid Community Quality Services Act" proposes the use of Medicaid to fund community and family support services as an alternative to the institutionalization of children and adults with disabilities. This bill also supports job training, respite care and other programs that help citizens with developmental disabilities to live in their own communities. The "Americans with Disabilities Act" was introduced in Congress in 1988 with the intent of prohibiting all discrimination on the basis of disabilities.

Federal laws already enacted and those proposed cannot succeed without strong leadership by the Executive branch of government. You know that each law requires adequate funding and consistent Federal monitoring so that the expanding opportunities can be available to citizens with disabilities of all ages wherever they and their families reside. Your administrative appointees to the critical Federal offices that develop and support the various Federal programs and services need your consistent support and leadership so they can carry out your policy commitments to people with disabilities and their families.

We look forward to your Administration taking the initiative to see to it that the American values of individual freedom of choice and involvement in the social, political and economic mainstream are applied to programs for individuals with disabilities. We believe that the gains our society has already made provide you and your Administration with the unique opportunity to complete this long overdue task.

We are prepared to work with you towards these goals by continuing to inform our readers of the activities of the relevant Federal government agencies and programs and by encouraging our readers participation in the democratic process. We wish you well.

Marshall S. Schleifer

Stanley D. Klein

Founders and Editors of EXCEPTIONAL PARENT

PARENTS RESPOND

The following letters are in response to E.D.'s request for information about Rubinstein-Taybi syndrome (Parents Search, November/December 1988).

RUBINSTEIN-TAYBI SYNDROME

I am responding to the letter in November/December 1988 issue of EXCEPTIONAL PARENT from the parent, E.D., of Florida, about Rubinstein-Taybi syndrome. We, too, have a son diagnosed with RTS. He is five years old now and doing much better than we were told he would do or that we had expected him to be able to do. He is a happy, active five-year-old with numerous health problems and developmental delays, but he continues to smile and share his love with so many.

We started a parent group for parents with RTS children in 1984 and we now have over 90 families that we correspond with here in the United States. Our group's name is Rubinstein-Taybi Parent Group (or RTS Parent Group). There are also parent contact groups that we know of in Ireland and England. We all enjoy sharing with each other about the difficulties and rewards that we have in caring for our children, and the help that we have received from everyone in the group has been a positive force for us through the past five years since our son was born.

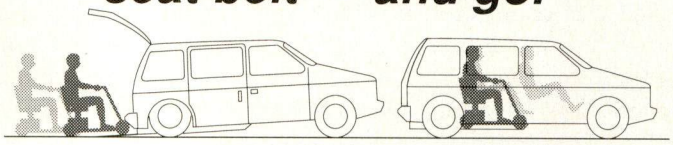
Our group just completed helping with a study on RTS this past spring and we are all anxious to see the final results made into a booklet for parents and professionals on how it is to care for a child with Rubinstein-Taybi syndrome. We are also in the beginning stages of planning a national meeting on RTS with a possible date of spring, 1990. Also, NORD has a very good DataBase Sheet on RTS with very basic information for anyone who has interest in RTS.

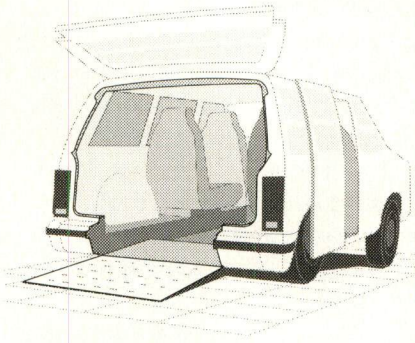
We have had letters in the past in EXCEPTIONAL PARENT about us and our parent group. The magazine has been a very big help to us as parents of a child with a disability and to our group in letting others know about our existence. We always appreciate what you do and have done for parents and families of children with disabilities.

If you know of other parents with RTS children or would like to let others know about our group, please use our letter in the magazine. We haven't sent a letter for quite a while. We look forward to the next issue of EXCEPTIONAL PARENT and thank you for what you do!

Lorrie Baxter
RTS Parent Group
414 East Kansas
Smith Center, Kan. 66967
(913) 282-6237

Just glide inside, fasten your seat belt ••• and go.





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CHRYSLER MOTORS

I noted your letter in the November/December 1988 issue of EXCEPTIONAL PARENT.

I continue to try to gather information about as many individuals with the syndrome as I can. I am therefore sending you two questionnaires, one for you to fill out and one for the doctor that knows most about Alberto. I will need to see photos of Alberto and copies of x-rays of his hands and feet.

I look forward to hearing from you.

*Jack H. **Rubinstein**, M.D.*
Director, Cincinnati Center for Developmental Disorders
Elland and Bethesda Avenues
Cincinnati, Ohio 45229-2899

I saw your letter in EXCEPTIONAL PARENT magazine regarding your son, Alberto. We, too, have a son with R/T syndrome. His name is Matthew and he is five and a half years old.

Like you, we were not given much information on the syndrome at first. Because of a letter I wrote to EXCEPTIONAL PARENT five years ago, I have been linked up with 95 other families in the U.S. and I am aware of a group in England and Ireland. I have corresponded also with Dr. Jack Rubinstein, the man who named the syndrome.

Lorrie Baxter is the head of our parent support group. She will send you all the information she has and send you a sheet to fill out on your son whereby you can share with all of us your knowledge and things you've learned through being an R/T parent.

Our son is a joy to us. He has had thumb surgery and testes surgery. He is generally quite healthy. At five and a half, he is probably at the two-and-a-half-year level mentally. He walks, runs, uses sign language and talks quite a bit. He is very small for his age.

Please write me if I can be of any help. Be sure to write to Laurie and welcome to the RTS support group!

M. S.
California

This letter is in response to the Parents Search article on Rubinstein-Taybi syndrome in the November/December 1988 issue of EXCEPTIONAL PARENT. Further information concerning Rubinstein-Taybi syndrome should be available from:

Little People of America,
National Headquarters,
Al and Harriet Stickney,
Box 633, San Bruno, Calif. 94066
(415) 589-0695

Marilyn A. Cohen/Coordinator
Regional Cleft Palate Program
Cooper Hospital/Univ. Med. Ctr.

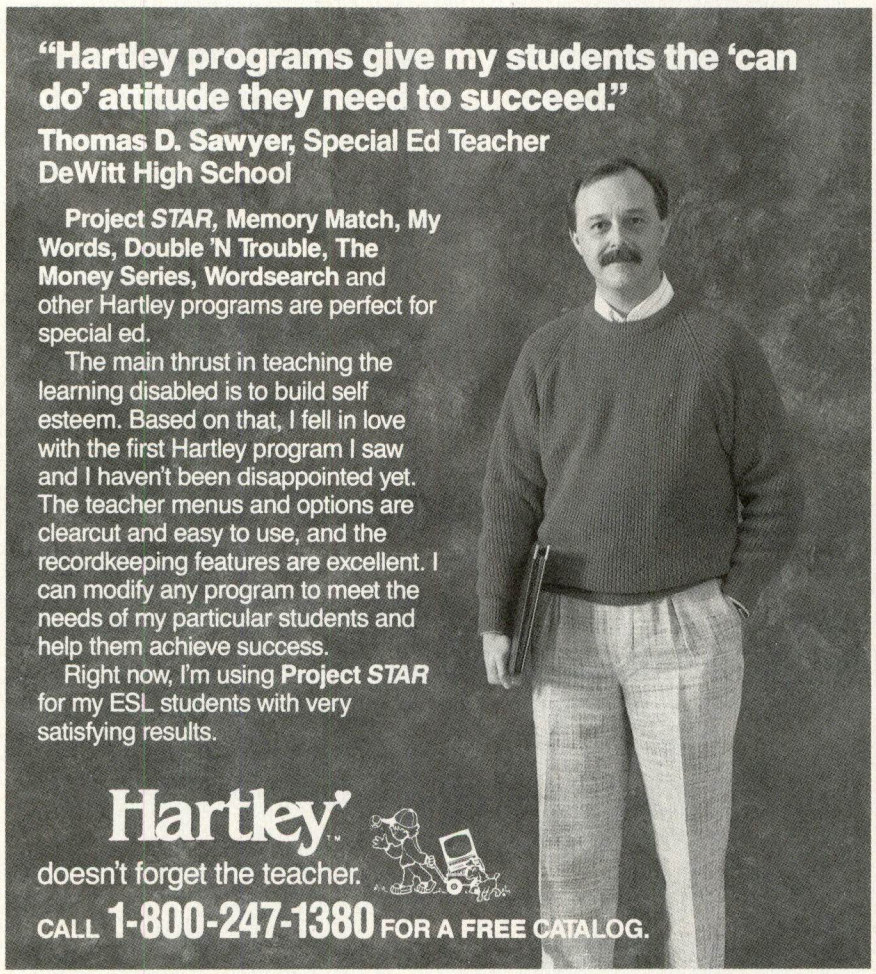
EHLERS DANLOS SYNDROME

The following letter is in response to M.H.'s request for information about Ehlers-Danlos syndrome (Parents Search, November/December 1988).

I read the letter from M.H. of Tennessee asking for information about Ehlers-Danlos syndrome type IV in your November/December 1988 issue.

I am sending a packet of material about the disorder to M.H. EXCEPTIONAL PARENT is always welcomed here, and has become "must" reading material for me. Keep up the excellent work. I'm sure you have helped thousands of people already.

Nancy A. Rogowski,
Executive Director,
Ehlers Danlos National Foundation,
P.O. Box 1212,
Southgate, Mich. 48195



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THE CHILD I LOVE MOST

A mother answers an important question.

By Jo Koles

"Mom, you love Carol most, don't you?"

I look up from the bills I am paying, wondering to myself, why at 3:30 in the afternoon my 14-year-old son, Tom, would ask that question. Stunned for a moment, I ask him the question again to be sure I understand what he is asking. Like many mothers, I have been known to answer when I have not fully heard or understood the question. He repeats it and he wants to know why I love his sister most.

Looking over to Carol, I think, "You better be honest with this kid, he's concerned, and he wants an answer."

Pushing the bills aside, I motion for Tom to sit down beside me, while I frantically think of a way to assure him, without hurting Carol.

"Tom," I said, stalling for time, thinking to myself that a phone call now would be helpful. "I don't understand how you could question my love for you."

"I know Mom," he says without conviction, "but you seem to love Carol more."

"Well Tom, let me explain it to you this way — I love you all most." Before he could respond with an attitude of being brushed off, I continue.

"You're right. I love Carol most; I love her most because she is my first born; the first child holds a very special place in a mother's heart. They are the "experiment" of more to come. They endure the trial and errors of parenting: the overprotectiveness, the sternness and the inexperience. I love her most because she is my only daughter, and she will someday be a woman, with whom I hope to have a friendship. I will always love her most.

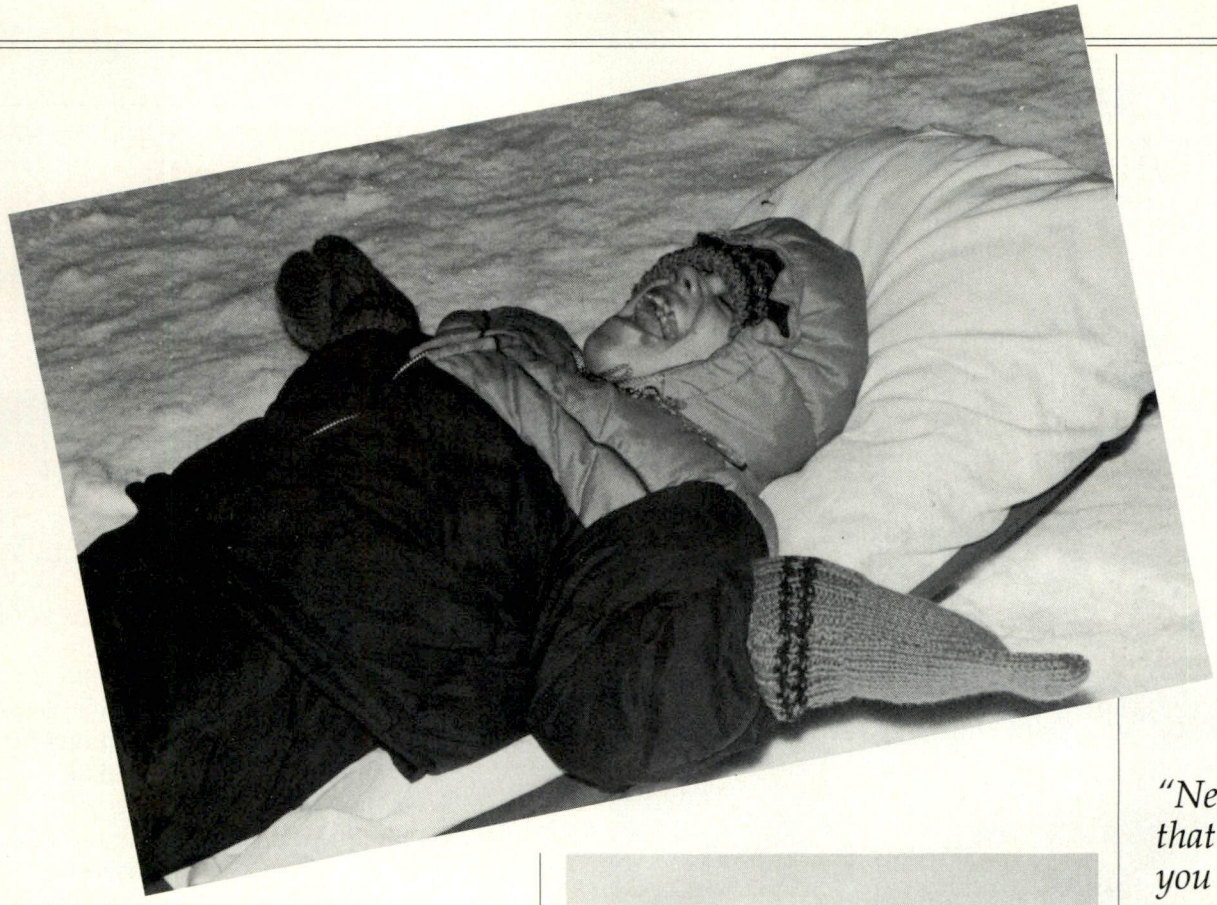
"Tom, I love you most. You are the middle child; you are my first-born son. You are the child who I could relax with and enjoy; knowing that you weren't going to break, I could delight in your antics.

"You have a special place in my heart because you are a middle child. I can relate to that position in the family because I, too, am a middle child. I know the "too old, too young syndrome," having to wait while the youngest is cared for or the oldest is run with. I take you for granted, assuming that because you are the center of the entire family in your birth order, you are secure.

"I will try not to assume that in the future, and I will take into consideration the independence you must want and the frustrations you must feel. I take pride in you and who you are. You have the ability to love and stay loving under so many circumstances. I love you most.

"Tom, I also love John most. He is the youngest, his needs are greater than most. He is special, as you know, because his needs are needs that cannot wait. His life is centered around constant care and loving; he is dependent upon all of us for the very drink of water that we take for granted.

"I don't love John most because he is disabled; I love John most because he, himself, is a loving person who delights in every facet of his life. I love the way he trusts us to meet his needs without

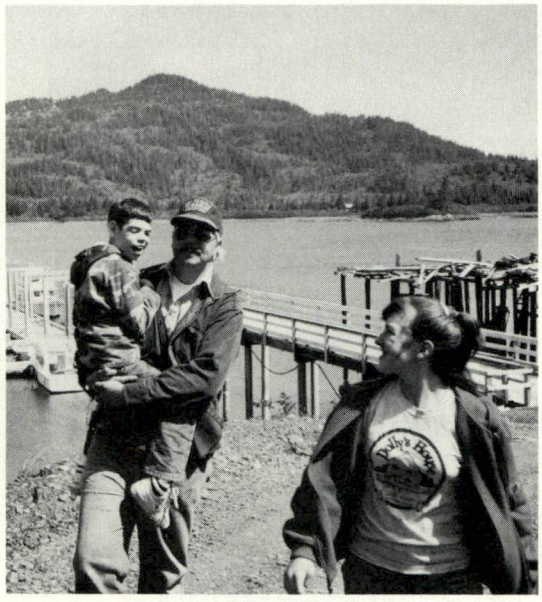


John enjoys the Alaska climate.

demanding, he trusts us as much as we should trust God to meet our needs. I love John the most because he teaches me to enjoy the simplicity of the day and to be thankful for the children we have who can run, jump, play, attain good grades, verbalize their joys and share their fears. I love John most for being a teacher to me.

"Tom, never doubt that I love you the most — not more, not less, than your sister and brother. I love you most. Each of you is a one-of-a-kind, limited edition that deserves in your own right to be loved most."

I look to Tom waiting for a response. He reaches over to hug me, then gets up and goes about his day.



John and Carol walk with their father.

Jo Koles, pictured above with her father, Thomas Cosgrove, is a free-lance writer and mother of three children, Carol, 18, Thomas, 15, and John, 13, who has cerebral palsy, epilepsy and a visual impairment. Jo and her husband, Justin, live in Anchorage, Alaska, and are active boaters on Prince William Sound.

"Never doubt that I love you the most — not more, not less, than your sister and brother."

C.A.M.P.

NEW HORIZONS

1988 AWARD WINNING SUMMER PROGRAMS

Summer provides children with a break from the restrictions of the classroom and provides an opportunity for innovation in many areas of skill development. Summer programs, without the rigid structure of the school year, can place more emphasis on developing recreation and social skills.

The programs chosen to receive EXCEPTIONAL PARENT's recognition as award winners provide creative opportunities for learning and growth in important areas affecting the lives of children with disabilities.

- **Timber Trails**
  A Girl Scout camp that truly integrates girls with disabilities into the traditional camp experience.

- **HASC Summer Program**
  Campers with disabilities are encouraged to bring their brothers and sisters to camp as counselors, allowing siblings to learn, grow and play together.

- **Children's Association for Maximum Potential (C.A.M.P.)**
  Located on a U.S. Air Force Base, this camp is able to serve children with severe disabilities and medical conditions by recruiting both military and civilian volunteers.

- **New Horizons**
  This year-round program provides a wide variety of social programs. for people with developmental disabilities from age six to 60.

HASC SUMMER PROGRAM

TIMBER TRAILS

TIMBER TRAILS

The summer of 1988 marked the fourth consecutive year the Connecticut Valley Girl Scout Council's resident camp, Timber Trails, ran its summer program for girls with disabilities.

Located in the foothills of the Berkshires in Tolland, Mass., the camp provides a variety of program options, including Farm Living, Project Adventure, equestrian, aquatics, gymnastics, dance, radio, photography, arts and crafts, Brownie Tasters and Junior Sampler, for girls entering grades 1-12. Program Aide Training and Counselor-In-Training programs are also available for girls 14 1/2 and up. Timber Trails operates for eight weeks each summer serving girls in one, two, three and four-week sessions.

As part of the disabilities program, girls with disabilities have been mainstreamed at Timber Trails for the past four summers. This summer 50 campers with physical, medical and/or learning disabilities and/or mental retardation attended. Timber Trails is unique in its ability to provide an experience that truly mainstreams *all* campers.

Outreach is done to all Girl Scout council members through a camp folder and the council newsletter. Community outreach is done through special educators, organizations that serve children with disabilities and local newspapers. The council disability specialist answers questions and evaluates whether a particular child would be appropriate for the camp program. Input from parents and teachers is obtained through a special camp application.

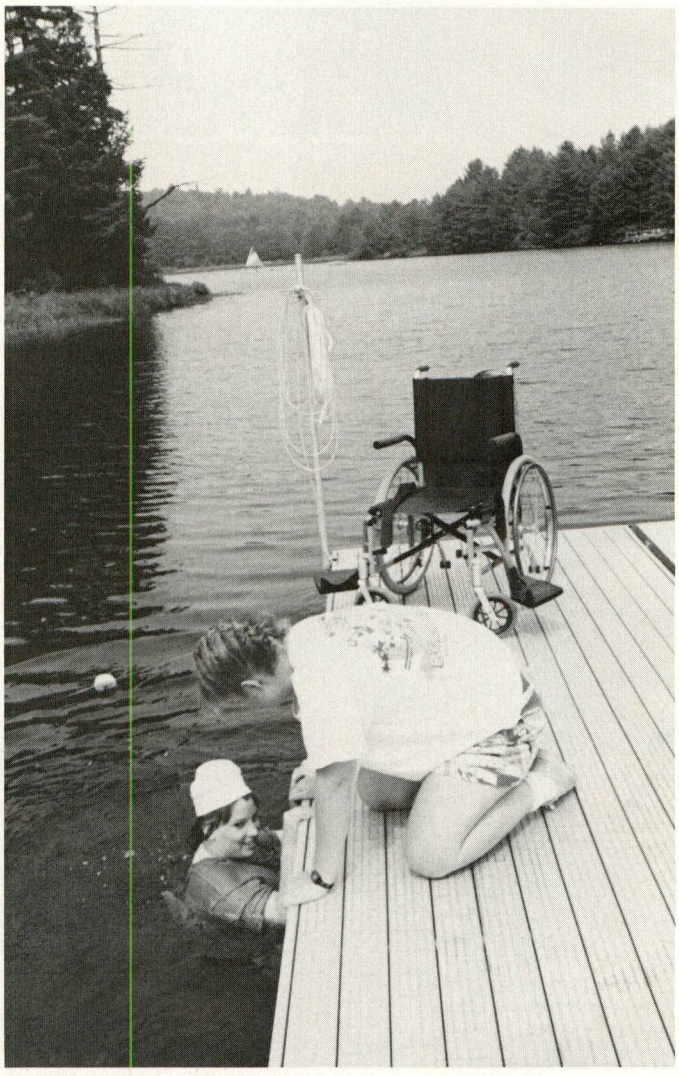
Girls with learning disabilities, epilepsy, asthma, diabetes, spina bifida, cerebral palsy, muscular dystrophy, traumatic brain injury, hearing impairments, visual impairments, Down syndrome, developmental delay and neurological impairments have all been successfully mainstreamed. All campers with disabilities live in units with other girls of the same age who are enrolled in the same programs.

Girls with mobility impairments are transported around camp by means of a donated station wagon. Ramps have been built in about one-half of the units, in the infirmary and in the two program centers, which also serve as dining halls. This past summer, a new building, which was built with funds donated by the Greater Hartford Jaycess, was opened and dedicated, making the arts and crafts, radio and photography programs completely accessible to all campers.

Each summer the camp staff includes a disabilities coordinator who works directly with the council disability specialist to meet the needs of each camper in the program. Together they provide a general disabilities awareness training session for all staff and ongoing training for individual staff members who work directly with each camper with a disability. Workshops in therapeutic riding have been provided for riding staff, and the barn area has a wheelchair ramp. The disabilities coordinator, with the help of staff members and volunteer aides, provides personal assistance to campers as needed.

The many benefits for campers and staff, with and without disabilities, have been evident. Timber Trails staff members, many of whom have never worked with children with disabilities before, come away from camp with a positive attitude.

Waterfront staff successfully adapted a canoe to accommodate a camper who uses a wheelchair. Dance



Waterfront activities are accessible to all campers.

Timber Trails mainstreams girls in a wide variety of programs.

instructors prepared a camper to perform in her first dance show — from her wheelchair.

Many of the campers with disabilities come to Timber Trails as their first away from home experience — and very often as their first experience with non-disabled peers. All campers at Timber Trails take turns being "hoppers" in the dining hall (setting tables, serving food) and doing unit "kapers" (cleaning bathroom areas, etc.) All campers at Timber Trails take swimming lessons, go boating and participate in a variety of camp programs. *All* campers develop new skills, increase their self-esteem and make new friends.

Although some campers with disabilities go on to become active members of Girl Scout troops, it is not necessary for a girl to be a member to attend the program at Timber Trails. Girl Scout camping programs are open to all girls age six through seventeen.

This summer Timber Trails had its first Program Aide with a disability. Kim was the first camper with a disability mainstreamed at Timber Trails five summers ago, before the special program for girls with disabilities had even begun.

Kim, who has spina bifida, then used her crutches to work her way around camp and was transported in the camp golf cart. She returned each summer and was successful in a variety of camp programs and settings. This summer Kim served as a Program Aide in the arts and crafts program in the new Jaycee Building.

For more information about Timber Trails summer program for girls with disabilities, contact Linda K. Miller, disability specialist for the Connecticut Valley Girl Scout Council, 74 Forest Street, Hartford, Conn., 06105, (203) 522-0163.

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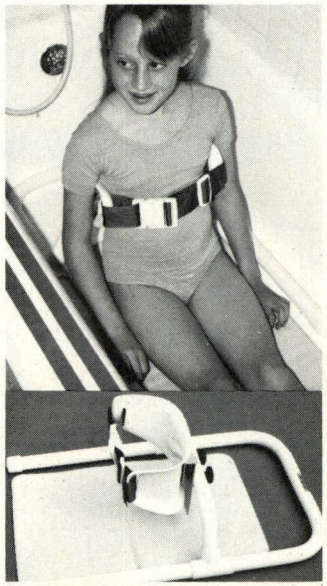

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HASC SUMMER PROGRAM

The HASC Summer Program is a special camp for children with multiple disabilities and severe mental retardation. Originally started as an outgrowth of the Hebrew Academy for Special Children, an independent, private, non-sectarian school for special children, at present, it is an independently chartered camp that serves special children from all over New York state and many from out of state as well. Historically, the camp has served, among its many children, a large number of children from the Orthodox Jewish community of the New York City area.

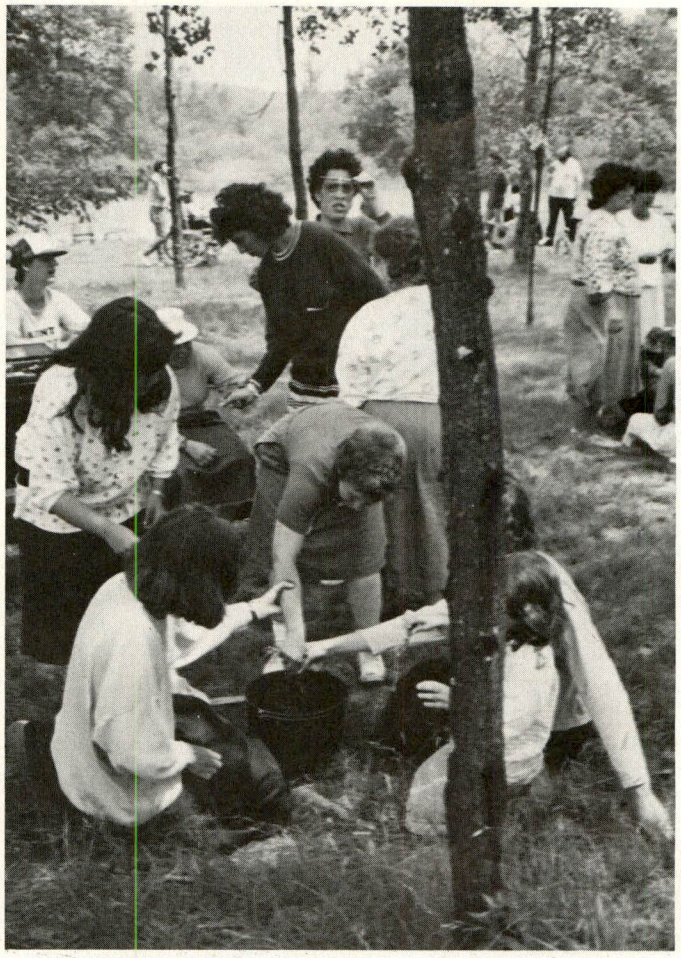
The camp, located in Parksville, N.Y., is situated in the Catskill Mountains. The HASC Summer Program is two-fold: a summer school program complete with special teachers, therapists and ancillary services as well as a full camp experience replete with counselors, specialty counselors, adaptive sports counselors and nature experiences common to any other summer camp. The education and training of the children is lifted from the limits of the classroom and the confines of the home and placed into the overall natural living pattern of the special individual.

There is integration of both components of the camp experience, namely, the academic and the recreational. The campers' Individualized Education Plans are carried out by the special education teachers and therapists with the assistance of aides, who are also the counselors in charge of the recreational component of the program.

Thus, continuity of instruction is woven into the fabric of the daily camp experience, be it language development, activities in daily living, adaptive motor experiences, sensory perceptual development or prevocational preparations. The enhancement of the camp experience is provided through daily activities of camp fires, dramatics, overnight trips, socials, carnivals and other special events.

The camp has several innovative programs with far reaching aims. These special programs have to do with cultural identity, social connectedness, emotional growth and community mental health.

The first of these programs encourages the siblings of these children with severe disabilities to join the camp as counselors and learn professional techniques of stimulation and education that enable each child to maximize his/her strengths and to develop in the deficient areas to their fullest capacity. Even more important, it fostered a shared closeness with the siblings and encouraged the development of healthy social and emotional growth through shared experiences. These siblings have become passionate advocates for the rights and needs of special people.



HASC campers enjoy a cook out.

The second program extends mainstreaming into the camping community to provide integrated experiences for this population of children with disabilities. The HASC Summer Program is located in an area that has several other children's summer camps. These camps were approached with a program aimed at raising the consciousness of their children regarding their special peers.

Interested counselors in training (CITs) from the other camps volunteered a few hours a week to work with campers with disabilities and their peers on joint projects in the flower and vegetable garden at HASC Summer Program. Similarly, they volunteered to work on other projects such as canival and dramatics. Ball clubs and sport groups from other camps came to play games in integrated intramural sport events. And most impressive, two HASC campers were then invited to spend two weeks integrated with their peers in a regular bunk in one of the area camps following the preparation of the children after the joint activities.

Teamwork and woodwork training, just one of the many camp experiences at HASC.

The third program reaches into the cultural identity and personal roots of the children, many of whom had limited participation in ethnic and cultural events due to their disability. A number of children at the camp came from Orthodox Jewish homes, but were never taken to the synagogue and had not experienced the rite of passage of becoming Bar Mitzvah.

During the summer, the HASC Summer Program celebrated the Bar Mitzvah of those children whose 13th birthday fell in the preceding year. The occasion was marked with festive celebration, invitation to family and friends and a special religious service at the camp. The day culminated in a gala dinner complete with singing and dancing.

Finally, the impact of the experience at the HASC Summer Program was seen in the determination of its counselors to involve the campers year-round in their communities. Moreover, these young men and women will set the tone on college campuses for further advocacy for persons with special needs and the initiation of programs for their integratation into their community.

For more information about the HASC Summer Program, contact Director Bernard M. Kahn, Parksville, N.Y. 12768, (914) 292-6821, or off-season at P.O. Box 119, Brooklyn, N.Y. 11219, (718) 851-6101.

Tadd and his friend Seth enjoy spending time together in the school library.

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C.A.M.P.

Children's Association for Maximum Potential (C.A.M.P.), based on the Lackland Air Force Base in San Antonio, Texas, is a unique program in that it accepts children with varying disabilities, particularly those children who have *not* been served by other camps for the disabled. C.A.M.P.'s goal is to accept each and every severely involved child, even if it means that the child is discharged from and returned to the hospital after camp.

C.A.M.P. was founded in 1980 when Dr. Chris Johnson saw a need for a camp that would accept severely disabled and mentally fragile children. San Antonio, the home of three major medical centers, has more than the usual number of children with involved medical problems. Dr. Johnson envisioned C.A.M.P. as a program that would serve this group of children: C.A.M.P.'s motto — no child is "too involved" to attend.

In C.A.M.P.'s first year, three doctors, six nurses and 40 high school and college students volunteered to take 50 children on a week long camping session. The program has since grown to three one-week sessions and two weekend sessions serving more than 475 children. In 1989, the program will be expanded to six to eight weeks due to the growing need for such a service.

Volunteerism makes it possible to serve so many children. At each camp, 20-25 nurses and six-ten doctors volunteer their time to work at the camp. The nurses and doctors dispense medications, work at the infirmary, conduct night rounds, assist at the activities and make friends with the campers. The camp setting gives the medical staff an opportunity to observe and interact with the campers at their best in a setting outside the hospital.

The practical learning experience is enhanced by an approved Continuing Education Program that is conducted at the camp. Three hours of didactic instruction and one hour of practicum account for 21 hours of credit per week. Each day a different disability (i.e., spina bifida, cerebral palsy, cleft palate) is discussed in depth. Afterward, each staff members is required to observe and work with a child who has the disability discussed that particular day.

The camper-staff ratio is 1:1. An excellent group of teenagers, college students, teachers, professionals, retired individuals and active-duty military personnel volunteer their time to work with the children. Pushing wheelchairs, feeding, changing clothing, showering, toileting and assisting at the activities are all part of the volunteers' responsibilities. Activities included horseback riding, archery, canoeing, swimming, riflery, and arts and crafts.

In pre-camp training, such topics as wheelchair maneuvers and transfers, seizure precautions, lifting techniques, and the campers' need for extra liquids, as well as other safety and first-aid related items, are covered. The pre-C.A.M.P. training supplements a six-week Child Care Course taught by physicians, nurses, therapists and special education teachers that all new counselors take prior to the summer sessions.

One of the goals of C.A.M.P. is to provide parents an opportunity for respite. Most parents eagerly take advantage of the break. For many of them the week is their "special time" with their other children. A popular aspect of the respite goal has been the addition of a Parent Retreat coordinated through the Lackland Air Force Base chaplain's office. While the children are at camp, the parents participate in a recreational/educational retreat at a nearby camp.

The parents have an opportunity to interact with other parents who have children with disabilities. Horseback riding, swimming, fishing, canoeing and plenty of leisure time are offered. Also, workshops are conducted that focus on family relationships and subjects relating to families with a child with a disability. When the retreat and camp end, both parents and children are better prepared to face the challenges that lie ahead of them.

C.A.M.P. is available to both civilian and military families. Because many families have transferred and volunteers have moved, knowledge of C.A.M.P. has spread across the United States and overseas.

Volunteer Carol Bova works with a camper in the water.

Counselors Paul Sheffield (left) and Dan Watson help camper Lee Oliver mount a horse.

Most camps for children with disabilities share the first two of C.A.M.P.'s "4-R" goals: recreation and respite. However, C.A.M.P.'s staff is approximately 35 percent professional medical staff, allowing the accomplishment of the third "R," which stands for rehabilitation.

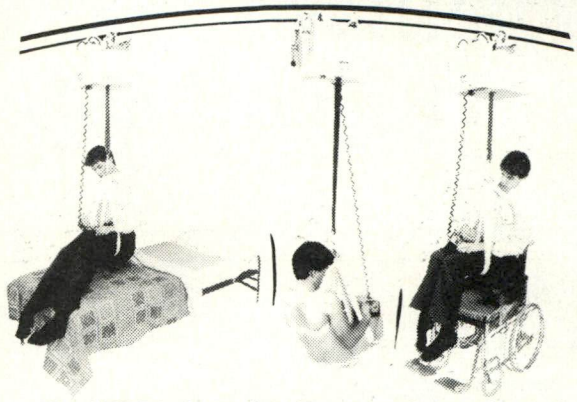
The doctors, nurses, therapists and teachers help each child (who is able) accomplish some rehab goal while he/she is at C.A.M.P., whether it be self-catheterization, wheelchair transfers, dressing or feeding skills. The fourth and final "R" that is reorientation. Through the continuing education program, C.A.M.P. hopes to reorient the professional community (as well as the student counselors) to what it is like to live with a child with a disability. At C.A.M.P., they learn the many stresses that parents must cope with on a daily basis.

The C.A.M.P. program has also expanded in related areas to fill the needs of the families. The expansion includes a year-round Child Development Center, a monthly Camp Brother/Camp Sister Program, a monthly Parents' Night Out, a social work program and an equipment loan program.

C.A.M.P. serves as a role model for other programs around the country. This last year, Dr. Chris Johnson, founder and executive director of C.A.M.P., was selected as "Pediatric Advocate of the Year" by *Contemporary Pediatrics* for her excellent work with C.A.M.P. Dr. Johnson is the executive director of C.A.M.P. and does so as a volunteer.

For more information about C.A.M.P., contact C.A.M.P. Program Director, Pat Kozar, Lackland Air Force Base, San Antonio, Texas 78236-5000, (512) 671-2598.

INDEPENDENCE



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NEW HORIZONS

The YMCA New Horizons program is a social and recreational program for persons in Orange and Los Angeles Counties, Calif., with developmental special needs, such as autism, cerebral palsy, epilepsy and mental retardation.

Since 1974, New Horizons has been committed to the philosophy that the community must provide constructive leisure-time activities for its citizens with disabilities New Horizons is unique because it operates year-round and offers a wide range of activities. In 1986-87 alone, the New Horizons program provided over 12,000 hours of activities for over 1500 participants.

The New Horizons program consists of four major types of activities:

Nite Owl Excursions are weekly evening programs to such locations as county fairs, professional and collegiate athletic events, theater and dance productions and other events. Participants are involved for an eight-week program and may re-enroll every session.

Week-end Caravans are overnight weekend trips to such areas as the local mountains for a ski trip or to the beaches. Participants are introduced to a new activities, such as camping skills and, most importantly, independent living skills situations.

Six-Day Caravans are extended camping trips to various locations in Arizona, Utah, Nevada and California, with the emphasis on sight-seeing, group skills and camping skills.

Special Caravans are major trips offered three to four times a year to such locations as Hawaii, Mexico, Washington, D.C., or Disney World in Florida.

The age range for our programs is from six to 70 for our travel trips. Our evening excursions are for participants 15 years and older.

The New Horizons programs also provide respite for the parents and care providers of the participants.

New Horizons families may also receive funding from the Developmental Disabilities Center. The DDC is a state funded, nonprofit organization for persons with developmental special needs. This organization will fund New Horizons caravans as a respite for parents allowing the participants to go at no cost to the parent. Participants, on the average, can attend one caravan a month through the DDC contracts.

The variety of age-appropriate activities offered at New Horizons allows a participant to have something to look forward to whether it ends up being the "night out on the town" or the "weekend of camping." New Horizons offers the participant many different environments in which they can put to use their skills from school or workshop. New Horizons programs reinforce the importance of "self worth" with the "I, too, can go camping," or "I, too, can travel with my friends" attitude.

Social and recreational training, such as "rolling a sleeping bag" or "cooking on a camp stove" are skills that a participant may never have had the chance to learn without the program. New Horizons informally trains participants in other skills, such as managing money, grooming and how to act and cooperate in a group situation.

Through the program there has been an increase in positive interactions they have with the general community. The community sees the population in a more favorable light, reinforcing the concept of "mainstreaming" the participant with special needs into the general environment.

As a result of being involved in recreational activities within the community, program participants may exercise a good deal of freedom of choice and independence. Participants are encouraged to act independently in all situations, but also have the assurance that the staff and volunteers will be there to assist them if necessary. The importance of practicing their social skills in actual situations is vitally important for the individual with special needs to ease their ultimate transition into the community.

New Horizons participants are able to learn purposeful and constructive leisure time activity skills that relate to community living skills. These skills allow the community to accept the special needs individual in a more positive manner, as well as enhance the participants' understanding of themselves and the community in which they live.

The year-round nature of the program allows a participant to continue his or her social/recreation training on a long-term basis. This has been shown to be the most effective method of acquiring new skills.

For more information about the YMCA New Horizons program, contact Program Director, Larry Herschler, New Horizons Building, 205 West Civic Center Drive, Santa Ana, Calif. 92701, (714) 547-4121.

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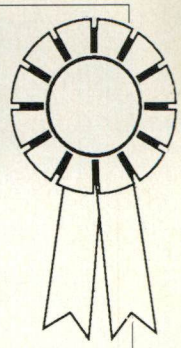

Announces the
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Technology and Everyday Life Award

Anyone can nominate a program for the Best School Mainstreaming Award. Please submit a brief description of any deserving program. Awards will be given in three categories: pre-school, grade school and high school.

The Technology and Everyday Life Award is open *only* to parents. Please submit a personal account of how technology has expanded the opportunities available to your child.

Maximum entry length for both contests: 1500 words. Please include pictures of program/child with your entry. Deadline: June 1, 1989.

Mail entries to:
Mainstreaming Contest
or
Technology Contest
EXCEPTIONAL PARENT
1170 Commonwealth Avenue
Boston, Mass. 02134

The winners will be announced in the September and October issues of

EXCEPTIONAL PARENT

1988 SUMMER PROGRAM COMMENDATIONS

With so many outstanding entries submitted to this year's summer program contest, it was a difficult task to chose only four EXCEPTIONAL PARENT Summer Program Award winners.

Because all of these programs do an excellent job of providing meaningful summer experiences for children with disabilities, we want to take this time to commend all of the program staff members and volunteers for their dedication and commitment.

- **Bay Cliff Health Camp**
  Harlow Block
  102 W. Washington Street
  Marquette, Michigan 49855

- **Helping Hands Day Camp**
  Phyllis Jackson, Director
  520 26th Street
  Virginia Beach, Virginia 23451

- **Rutherford County Camp B.E.S.T. (Bringing Easter Seals to Tennessee)**
  Carolyn Diane Moore, Director
  Smyrna, Tennessee

- **The Special Needs Day Camp**
  Erika Schwartzkopf, Director
  City of Middletown Parks and Recreation Department
  Lawrence School
  Middletown, Connecticut 06457

Mainstreamed campers play with soap bubbles at the UP with Kids program, run by the University of Portland.

- **Search Day Program, Inc.**
  73 Wickapecko Drive
  Ocean, New Jersey 07712

- **Summer Campus Institute on Augmentative Communication**
  Temple University
  Philadelphia, Pennsylvania.
  Sponsored by Temple University, Prentke Romich Company, Office of Vocational Rehabilitation, Innovating Worthy Projects and Semantic Compaction Systems

- **UP with Kids**
  Dvenna Duncan, Director
  The University of Portland
  School of Education
  5000 North Willamette Blvd.
  Portland, Oregon 97203

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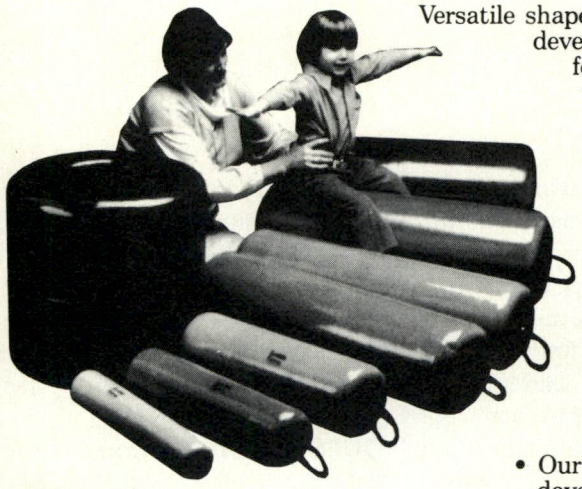

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PLAY TIME:

Meeting the needs of your child

Parents and professionals must collaborate to design effective recreation programs.

By Stuart J. Schleien, Cheryl K. Baldwin & Cheryl L. Light

Participation in recreational and social activities is an important aspect of life for children with disabilities. These activities can provide many opportunities: exposure to new friends, development of leisure skills, development of important skills such as motor, social and academic skills, and the enhancement of physical health and conditioning. Additionally, maladaptive behavior (e.g., tantrums, self-injurious behavior) is often reduced or eliminated as new recreational skills are acquired.

Although recreation programs for children with disabilities are usually designed by a therapeutic recreation specialist or special education teacher, the success of these programs often depends on the assistance of parents or other care providers. Parents have key information regarding their children's needs, abilities and personal preferences. Collaboration of parents and professionals is essential, because human service workers need to become aware of each child's characteristics, abilities and needs when designing effective programs.

Also, parents and care providers need to become familiar with the instructional techniques of a program in order to continue to develop their children's recreational and social skills at home. By asking the right questions, parents can learn about programs as well as contribute to them. The following questions enable parents to evaluate and contribute to the development of their child's current and future recreation programs.

QUESTION 1: ***Are the recreational activities consistent with your child's current skill level?***

Any recreation program should begin with an extensive assessment that provides an inventory of your child's abilities and needs. This assessment should identify your child's physical characteristics, the appropriateness and relevancy of planned activities and an indication of his/her proficiency in these activities. The criteria for developing a beneficial program includes your child's potential for success, how often your child will be given an opportunity to engage in that activity, and how the activity relates to other areas of your child's life.

The needs assessment becomes the "guide" for developing a complete recreation and socialization program based on your child's skill level and needs. Since the needs assessment is concerned with

demonstrated behaviors and abilities, it cannot be completed satisfactorily without input from parents, who are the most familiar with their child's use of free time.

QUESTION 2: ***Are your child's and the family's recreational preferences being considered?***

Before a recreation program is started, an attempt must be made to assess whether the planned activities are ones that your child and family presently enjoy or would enjoy together, provided your child had at least some of the skills necessary for participation. Your child is more likely to play appropriately with materials that he/she has access to and prefers. Preferred activities and materials may not be obvious to professionals.

As parents, you can provide helpful information concerning the interests of all members of your family. You can also offer the therapeutic recreation specialist or teacher listings of accessible materials your child seems to enjoy and activities he/she selects at home.

If you are uncertain of your child's preferences, several play objects could be presented to your child and the materials most often selected or manipulated, noted. This input can help professionals make informed decisions concerning materials to make available and possible skills to target for instruction.

QUESTION 3: ***Are selected activities both relevant and age-appropriate?***

Your child's recreational program should include relevant activities that will be useful and remain chronologically age-appropriate throughout his/her lifetime. For example, activities such as making a sandwich or playing pinball will remain useful and appropriate forever and could be pursued in a more sophisticated manner throughout one's lifetime. Similarly, cooking and table game activities are appropriate and important lifetime leisure pursuits that a person can enjoy alone or with others.

Also, these and similar activities typically promote social interaction with peers without disabilities, since acquisition of these skills results in compatible interests and repertoires.

For example, learning to play with a Lite-Brite™ toy (by Hasbro) would be more relevant and age-appropriate than learning to manipulate pegs in a peg board. Although both activities develop eye-hand

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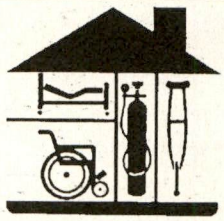

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Modifying activities and materials can increase your child's independence and provide for a wider selection of accessible recreational and social pursuits.

coordination through the placing of pegs in a peg board, the Lite-Brite™ also provides the child access to the activities of peers.

QUESTION 4: ***Do the recreational activities contribute to skill development in other areas?***

Ideally, the activities selected for your child should enhance the development of skills that are desirable for a variety of settings. Recreational activities could provide the ideal medium for expanding social, behavioral, communication, problem solving, and motor skills.

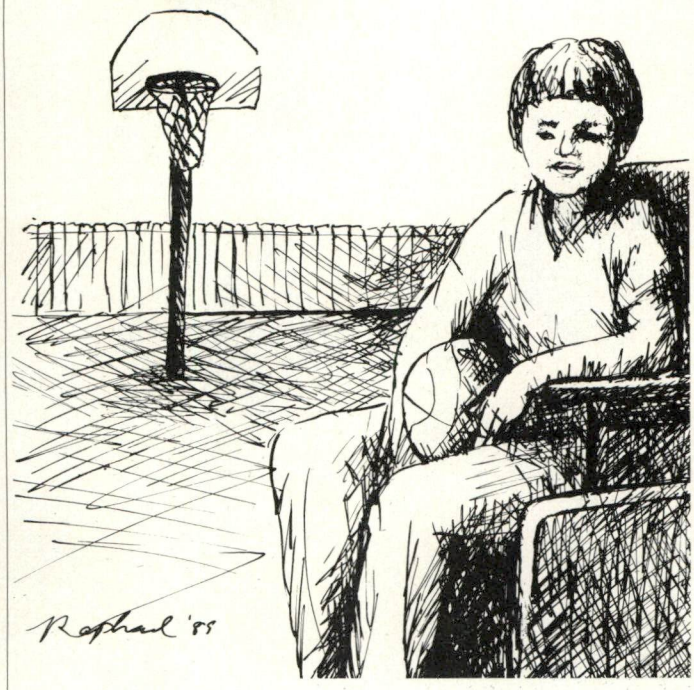
For example, the age-appropriate board game Simon™ (by Milton Bradley) involves the use of fine motor skills to manipulate switches in the game, gross motor skills such as arm extension to depress the panels, social skills to take turns and share materials, and cognitive skills to remember the order in which the plastic panels light up. Learning to play a game like Simon™ may also result in making new friends.

QUESTION 5: ***Are new recreational and social skills taught systematically?***

Facilitating involvement in recreational and social activities that are useful, age-appropriate and enjoyable for your child will probably require systematic skill training. Components of systematic instruction include careful observation of your child, task analysis, prompting and correction procedures, and positive reinforcement strategies.

In a task analytic approach, the targeted activity (e.g., horse-shoes) is broken down into its component parts (e.g., grasping horseshoe, pitching horseshoe, turn taking, measuring distance of horseshoes to stake/dowel) that are teachable and observable. Through the task analysis, the instructor determines which components of the activity your child can currently perform independently and the parts needing additional instruction.

Parents can become involved in this process by using similar instructional procedures when your child participates at home.



QUESTION 6: *Are effective activity adaptations being used?*

Modifying activities and materials can increase your child's independence and provide for a wider selection of accessible recreational and social pursuits. However, when modifying an activity it is always important to keep the activities and materials as normal or standardized as possible. A little creativity and innovation can make the adaptation process a fairly simple one.

There are four options that can be considered when adapting activities: 1) material adaptations (e.g., In an arts & crafts activity, using four-holed training scissors rather than traditional two-holed scissors); 2) rule or procedural adaptations (e.g., when learning to play tennis, allowing more than one bounce before returning the ball); 3) skill sequence adaptations, which focus on preparation before the actual activity, (e.g., when eating at a fast-food restaurant, one would be prepared to order a meal with picture cards before entering the restaurant); and 4) lead-up activity adaptations (e.g., learning to play kick ball before trying to master the game of softball).

Materials, rules or procedures, and skill sequences can be modified, as well as making the facilities, themselves, architecturally accessible. Parents are often familiar with ways of adapting materials and routines for daily living. This information can be very helpful to staff when designing and implementing such programs.

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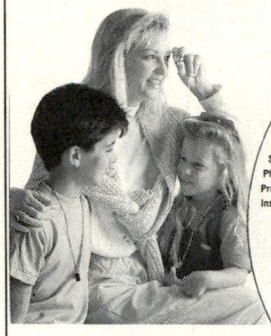

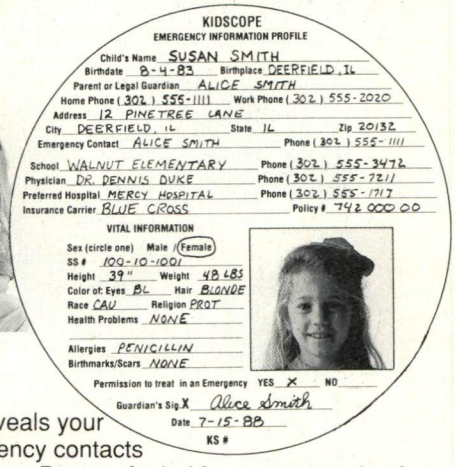

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QUESTION 7: ***Are your child's recreational and social skills being enhanced and maintained over time?***

If your child is not provided the opportunity to use his/her newly acquired skills outside of the training environment (e.g., school, community recreation center, physical education class, YMCA), it is unlikely that these skills will be maintained. It is critical that participation in the targeted activity be encouraged by professionals and parents in a variety of environments and with as many different people as possible.

An excellent way for parents and professionals to work together is to share resources. A loan-out system whereby parents check-out or borrow games or toys for a weekend (similar to a library book loan procedure) is a sure way to encourage recreational participation at home. Having your child bring some of his/her own play materials (e.g., favorite games, hobbies, cards, musical instruments) to the recreation program can also promote social interaction with peers and provide opportunities to practice previously acquired skills.

QUESTION 8: ***Is your child being integrated into existing community recreation programs?***

Participation in existing community recreation and social programs, along with the segregated programs that schools and community centers may provide, can greatly enhance the overall normalization process. As a participant in community-based programs, your child has the opportunity to interact

with peers without disabilities and with the community at large. Support should be provided for locating appropriate, architecturally and programmatically accessible programs. Often, a care provider or advocate can attend a program with a child for additional support and on-site instruction.

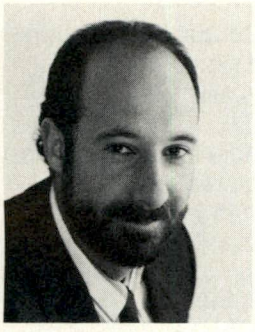
Recreational and social programming for children with disabilities is an ongoing process best achieved when cooperation and understanding between therapeutic recreation specialists, teachers and parents exist. Effective networking creates additional opportunities for your child. The opportunity to access different environments, to interact with peers, and to make friends are a few of the many benefits to participation in recreational and social programs. As parents and professionals become better acquainted and informed, program quality can only be enhanced.

For further reading on this topic, the authors suggest consulting the following publications:

Schleien, S. and Ray, M.T. (1988). Community Recreation and Persons with Disabilities: Strategies for Integration. Baltimore: Paul H. Brookes Publishing Co., $25.95.

Wehman, P. and Schleien, S. (1980). Assessment and selection of leisure skills for severely handicapped individuals. *Education and Training of the Mentally Retarded*, 15(1), 50-57.

Wuerch, B. and Voeltz, L. (1982). Longitudinal Leisure Skills for Severely Handicapped Learners: The Ho'onanea Curriculum Component. Baltimore: Paul H. Brookes Publishing Co., $17.95.



Stuart J. Schleien, Ph.D., is an associate professor of therapeutic recreation and special education at the University of Minnesota's School of Physical Education and Recreation. Dr. Schleien has written extensively on leisure/recreation, community integration and persons with developmental disabilities.

Cheryl L. Light and Cheryl K. Baldwin are staff members of the Therapeutic Recreation/Outdoor Education Integration Grant Project at the University of Minnesota. Both are currently graduate students in the University of Minnesota's Recreation, Park and Leisure Studies program.

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Directory of National Recreation Organizations

Accent on Information
P.O. Box 700
Bloomington, Ill. 61701
(309) 378-2961
Database information on recreation and disabilities available by phone. All searches charge a small fee.

American Alliance for Health, Physical Education, Recreation and Dance
Adapted Physical Activity Council
1900 Association Drive
Reston, Va. 22091
(703) 476-3430
Membership organization for recreation teachers and leaders. Publishes *Able-Bodies* newsletter that reports to membership on successful recreation programs, adaptations and methods.

American Camping Association
Bradford Woods
5000 State Road 67 North
Martinsville, Ind. 46151
(317) 342-8456
Accredits camps nationwide and publishes *A Guide to Accredited Camps* ($9.95), which lists over 2,000 approved camps, including listings by disability. Catalog of over 450 titles on camping and nature also available. Orders only, call 1-800-428-2267.

American Wheelchair Sailing Association
Duncan Milne
512 Thirtieth Street
Newport Beach, Calif. 92663

Association of Handicapped Artists
5150 Broadway
Depew, N.Y. 14043
(716) 683-4624
Company that markets cards and calendars of mouth and foot painters. Information on how to join, where to get supplies and adaptive equipment is available by calling or writing.

SCOUTING/USA

Boys Scouts of America, Scouting for the Handicapped
1325 Walnut Hill Lane
P.O. 152079
Irving, Texas 75015
(214) 580-2000
Open to any youth ages 6-20. Boy Scouts will adapt a program to the special needs of the youths involved and work with the parents for support, involvement and leadership. Contact the local Boy Scout Council.

Canadian Association for Disabled Skiing
Box 307
Kimberley, British Columbia,
Canada V1A 2Y9
(604) 427-7712
Governing body of nine provincial divisions. Specific programs within divisions, no age limits.

Canadian Recreational Canoeing Association
P.O. Box 500
Hyde Park, Ontario,
Canada N0M 1Z0
(519) 473-2109
More information available in videocassette or manual form.

Canadian Wheelchair Sports Association
160 James Naismith Drive
Gloucester, Ontario
Canada K1B 5N4
(613) 748-5685
Governs 10 sports, most with junior divisions. Programs start at age 8. Provincial branches in every province from which 80 juniors participate in competition at one central location.

Committee on Recreation and Leisure Newsletter
President's Committee on Employment of People with Disabilities
Washington, D.C. 20210
(202) 653-5044
Magazine aimed at employers containing a section devoted to recreation.

GIRL SCOUTS

Girl Scouts of the USA
Martha Jo Dennison
830 Third Ave. & 51st St.
New York, N.Y. 10022
(212) 940-7736
Open to all girls ages 5-17, kindergarten-12th grade. National office will help parents coordinate with local Girl Scout Councils.

Handicapped Scuba Association
116 W. El Portal, Suite 104
San Clemente, Calif. 92672
(714) 498-6128
Programs available to young adults. Participation requires another family member or adult to work with the person with a disability in a team.

HEALTHsports, Inc.
1455 West Lake Street
Minneapolis, Minn. 55408
(612) 827-3232
Ski for Light International, an event for blind, physically handicapped and guides. Program also sponsors events at local and regional levels.

I CAN Network
University of Virginia
Adapted Physical Education Program
221 Memorial Gymnasium
Charlottesville, Va. 22903
PE Helpline: (804) 924-6192
Responds to requests for information regarding physical education and sport opportunities for people with disabilities. Works to facilitate communication between athletes, parents, teachers, professors and students in the field of adapted physical education.

International Foundation for Wheelchair Tennis
Peter Burwash Associates
2203 Timberloch Place, Suite 126
The Woodlands, Texas 77380
(713) 363-4707
Connects wheelchair tennis players with professional players for lessons.

International Wheelchair Road Racers Club, Inc.
Joseph M. Dowling, President
30 Myano Lane
Stamford, Conn. 06902
(203) 967-2231
Keeps wheelchair road racers up to date on races and other events through newsletters.

The Itinerary Magazine
P.O. Box 1084
Bayonne, N.J. 07001-1084
(201) 858-3400
Magazine for travelers with disabilities, also organizes tours.

National Archery Association
1750 E. Boulder St.
Colorado Springs, Colo. 80909
(719) 578-4576
Nationwide program for children under 18. Membership application and more information are available.

National Foundation for Horsemanship for the Handicapped
Box 462
Malvern, Pa. 19355
(215) 644-7414
Advisory center for the evaluation of programs and the exchange of ideas and experience in therapeutic horsemanship. Sponsor of an international conference of riders with disabilities to be held September 1989.

National Handicapped Sports and Recreation Association
1145 19th St. N.W., Suite 717
Washington, D.C. 20036
(301) 652-7505
Family-oriented programs that focus on involving people with disabilities in various recreational activities. Fifty-seven chapters in 34 states, offering such programs as aerobics, skiing, and white-water rafting. Most programs are open to all ages.

The National Hookup
Ruth B. Meyette, Editor
32 Margaret Drive
Albany, N.Y. 12211
(518) 459-8563
Newsletter published by Indoor Sports Club for the Physically Disabled. Call or write for information or for a copy of the newsletter.

National Park Service
Division of Special Programs and Populations
P.O. 37127
Washington, D.C. 20013-7127
(202) 343-4747
Provides technical assistance for National Parks to improve accessibility to people with special needs, focuses primarily on correcting architectural barriers.

National Theater of the Deaf
P.O. Box 659
Chester, Conn. 06412
(203) 526-4971
Two touring companies: National Theater of the Deaf and Little Theater of the Deaf, a family oriented program that appears at schools and parks across the country. Tour schedules are available.

National Therapeutic Recreation Society
3101 Park Center Drive
Alexandria, Va. 22302
(703) 820-4940
Organization serving professionals, associates and agencies that provide recreational services to people with disabilities. NTRS also provides information on local resources and materials.

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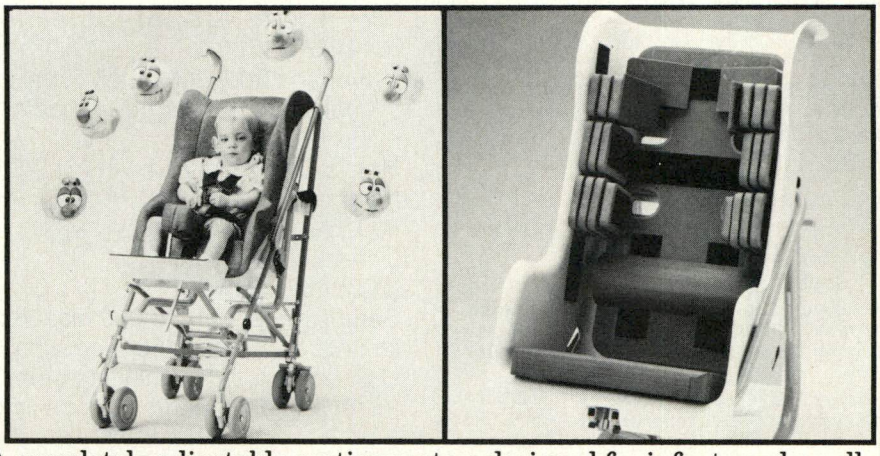

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National Wheelchair Basketball Association
110 Seaton Building
University of Kentucky
Lexington, Ky. 40506
(606) 257-1623
Juniors Division of NWBA available. Communities with existing youth teams receive information and development of the sport. Call or write for an appropriate program in your area.

National Wheelchair Games
National Wheelchair Athletic Assoc.
3617 Betty Drive, Suite S
Colorado Springs, Colo. 80917
(303) 597-8330
Competition limited to athletes 18 years and older.

National Wheelchair Softball Association
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(612) 437-1792
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National Federation for the Blind
2704 Beach Drive
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Quarterly magazine published by the Writers Division of the National Federation of the Blind. Subscriptions are available in cassette, large type ($5/year) or Braille ($10/year) format and include membership in the Writers Division.

Special Olympics, Inc.
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Suite 500
Washington, D.C. 20005
(202) 628-3630
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on Special Recreation
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Iowa City, Iowa 52246-3038
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(313) 425-8961
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United States Association for Blind Athletes
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United States Blind Golfers Association
c/o Patrick Browne, Jr.
300 Carondelet Street
New Orleans, La. 70130
(504) 522-3203

United States Organization for Disabled Athletes
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(813) 978-0101
Olympic-style national and international competition for youths ages 8-18, open to all disabilities. This year's Victory Games will be held August 1-8, in Tampla, Fla. Write for an application, or to participate call Al Orr at (813) 272-5732. To sponsor a child or for more information call Wanda LaVelle at (813) 978-0101.

United States Quad Rugby Association
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(701) 772-1961
Organizes competitive teams of quadriplegics, any age.

United States Wheelchair Racquet-Sports Association
Chip Parmelly
1941 Viento Verano Drive
Diamond Bar, Calif. 91765
(714) 861-7312
Purpose of organization is to promote awareness of wheelchair racquetball and provide information on programs and wheelchair racquet sports. Juniors program expected to start in the spring.

United States Wheelchair Weightlifting Federation
Bill Hens
39 Michael Place
Levittown, Pa. 19057
(215) 945-1964
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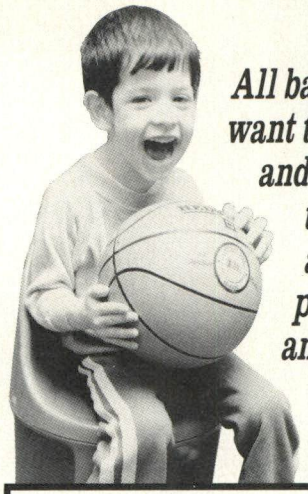
4-H and Youth Development
U.S. Department of Agriculture
Extension Service,
Room 3860-S
Washington, D.C. 20250
(202) 447-5516
Most programs integrate disabled children using the buddy-system approach. Children ages 7-19 years can participate. Contact your local county 4-H extension. Services and programs vary from county to county.



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EP 189

SWIMMING FOR SELF-CONFIDENCE & FUN

Guidelines for a community-based swimming program.

By Robert F. Bond

Jodie learned to roll over a few weeks ago. This would be routine progress for a six-month-old baby, but for Jodie it was an accomplishment comparable to running a four-minute mile. Jodie is a six-year-old girl severely afflicted with cerebral palsy.

Jodie was floating on her back in three foot deep water in a municipal swimming pool. While her instructor watched her carefully, Jodie raised her left hand in the air, one of the few controlled arm movements possible for her. This caused her to roll to the left. Then, by twisting her head and arching her back, she corkscrewed in the water and came up again on her back.

Her delight at moving her body in a controlled manner was obvious. She was giggling happily as the water streamed from her face. We all cheered as the instructor hugged the triumphant girl.

Watching the joy of a child move by herself, perhaps for the first time, is one of the rewards of participating in a swimming program for children with disabilities.

The program, staffed entirely by volunteers, is run under the auspices of the North Jeffco Metropolitan Recreation and Park District of Arvada, Colo., and the Mile High Chapter of the American Red Cross. One-hour classes are held each Saturday throughout most of the year. Emphasis is placed on teaching both children and adults with a wide range of disabilities to achieve standard Red Cross levels of swimming proficiency. Fees levied by the recreation district are nominal. Parents are responsible for bringing students to the class and for readying them for the water. The only requirement is that the student must be able to comprehend instructions.

The major focus of our program — and the major benefit to our students — is

Jill Jahnke, six, begins learning to swim under the guidance of Julie McGlothen.

to make them safe in the water. By teaching our students to swim, and swim well, we are hopefully preventing future drownings. We hope to train each student to swim well enough so that an accidental dunking in deep water would not result in a tragedy. Actually, most of the advanced students are better swimmers than the average recreational swimmer.

EXERCISE

Second in importance is the benefit of exercise. Children usually lead very active lives. Their high activity level builds muscles, bones and cardio-vascular capacity. Many children with disabilities are denied opportunities for exercise or their disabilities prevent them from exercising on land. Once trained, they are able to work out safely in the water, a cushioning medium. For some, water exercise may be the only unaided body movement possible. Some students have even commented: "The pool is the only place where I can walk."

Some youngsters with cerebral palsy, or other motor control impairments, cannot exercise strenuously on land for fear of falling and injuring themselves. Those who are wheelchair-bound often have not been trained in the sports that are possible for them. Children who are mentally retarded sometimes lack the attention span or grasp of rules that would allow them to participate in organized sports with other

CHILDREN WITH CEREBRAL PALSY NEED COMPREHENSIVE, INTENSIVE PROGRAMS

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Diane L. Gallagher, Director

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Nora Nickel guides Richard Lowe, six, in the beginner's stroke.

children. Because of these deficiencies, we find that many of our students have poor muscle development and lack stamina.

But most problems can be addressed with a structured swimming program. Once children are able to swim, they can exercise or be exercised safely in the pool. In the water, they are cushioned from damaging falls. Individuals who cannot use their legs can learn to do a very credible front crawl stroke, since that stroke gets little propulsion from the kick. Children with developmental disabilities can learn to swim well and most can participate enthusiastically in relay races. Adapted strokes can often be worked out for those with limited control of their muscles.

Of course, one workout per week is less than ideal. Once a student is water-safe, we encourage parents to take the child to a public swimming pool for his own exercise sessions, but this often cannot be worked into a busy schedule.

SELF CONFIDENCE AND FUN

Competency in swimming adds significantly to the child's self-confidence. For children who may not be able to play all the games their peers play, becoming better-than-average swimmers is a source of great pride.

One of the major high points of our teaching year is the day the children show us their ribbons from the Special Olympics swimming events. For some of the students, participation in the annual swimming Special Olympics serves as a goal and motivation to improve strokes and speed.

We also give each student a trophy at our annual Christmas party, awarding trophies for such accom-

plishments as "most improvement," "best crawl stroke" or "most willing worker."

Not the least of our aims is to enable these children to thoroughly enjoy themselves for an hour a week. Added to the simple physical pleasure of working muscles vigorously is the thrill of mastering a new and difficult skill. But while fun is a major component of the program, the students are not allowed to forget that they are there to improve their swimming abilities. While there may be 10 minutes of free time at the end of each session, the rest of the hour is structured instruction.

For children who may not be able to play all the games their peers play, becoming better-than-average swimmers is a source of great pride.

The students are separated into beginner and advanced swimmers. The advanced swimmers are taught in classes of four to eight, usually by one instructor who directs them from the deck. Beginners invariably receive individual instruction.

Safety is an over-riding concern. A person with a Red Cross advanced lifesaving rating is always on the deck or in the pool. When it is necessary for the trained lifesaver to be in the water, a safety lookout, who may be a parent, is assigned to watch from the deck and alert the lifesaver to any potential trouble.

ELEMENTARY STROKES

Formal training in swimming instruction techniques is not necessary for instructors working with beginning students. Those with American Red Cross ratings of Water Safety Instructor or Adapted Aquatics Instructor work with the advanced group. The instruction closely follows the American Red Cross guidelines. Beginning students are first taught breath control, rhythmic breathing and prone and back floats. The instruction then proceeds to the crawl or the beginner's stroke (a modified dog-paddle). Most youngsters can achieve proficiency in the crawl — the most useful and fastest swimming stroke.

A good deal of emphasis is also placed on the elementary back stroke — a very restful stroke that is especially useful in situations where survival is at stake. Care must be used in introducing students to back floats and back strokes. Young children are invariably uncomfortable on their backs in the water because they feel out of control. This can be especially true of students with physical disabilities.

Other water skills specified by the Red Cross, including surface diving, diving from the side, swimming under water, treading water, survival floating and use of personal flotation devices (life

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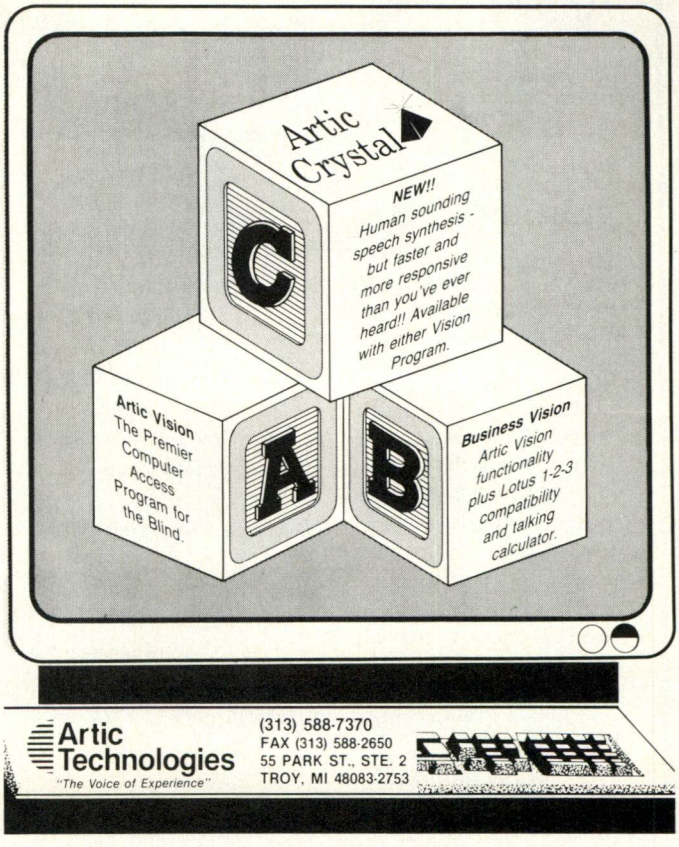

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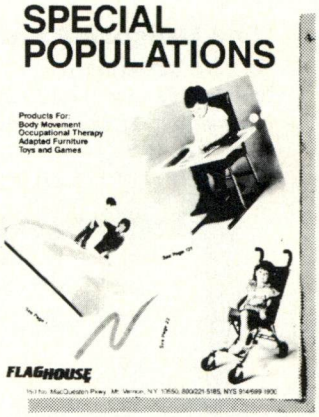

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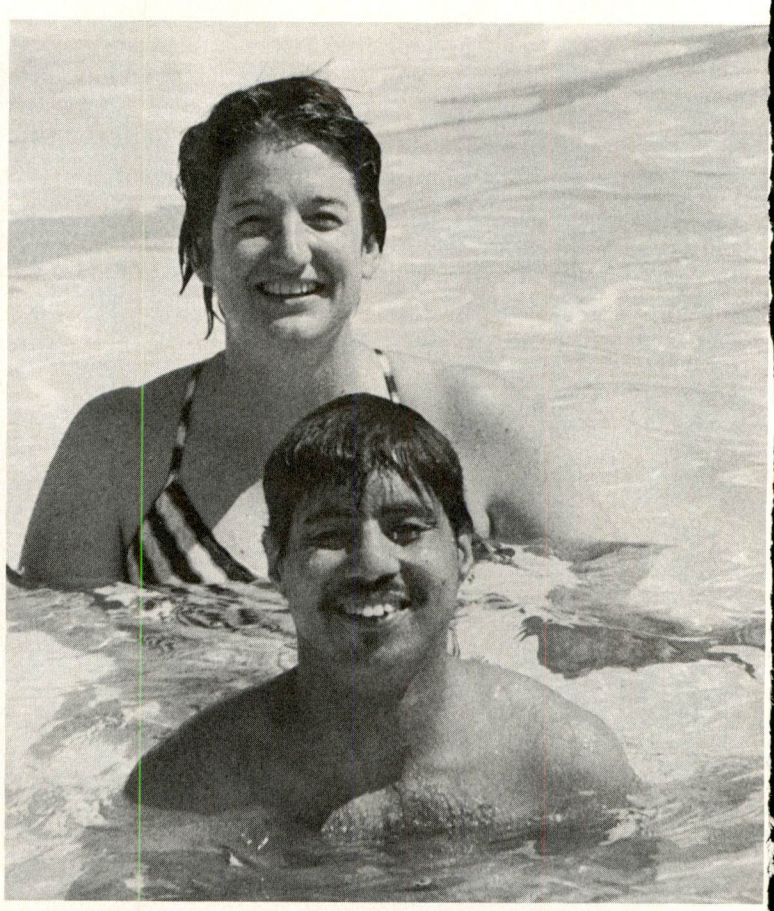

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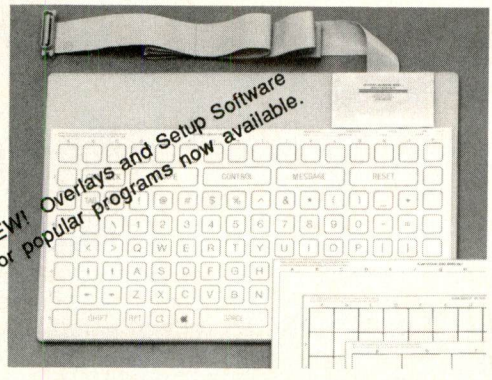

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jackets and ring buoys) are taught to all advanced students. Breast stroke, back crawl and other more complicated strokes are selectively taught to the most advanced students.

ADAPTATIONS

There are obvious adaptations necessary for various disabilities. One of our most significant problems is water temperature. We use a municipal swimming pool where the water temperature is kept at 82 to 86 degrees Fahrenheit. Children who are unable to generate much body heat through muscle activity get chilled rather quickly. A cotton T-shirt is a great help in retaining body heat in the water. Beginners are usually limited to half-hour lessons to minimize this problem.

Another obvious adaptation is the use of floats for non-swimmers. We use these very sparingly. If a student can be taught to stay at the surface in any way without flotation devices, we will not use them. The children come to depend on these aids, and they ultimately slow training. However, muscle rigidity increases specific gravity, and students with spastic paralysis often cannot float without swimming aids.

We have found that swimming goggles are also useful. The chemicals in the average public swimming

Advanced swimmers Goeff Fort, front, and Jeff Hardin, right, pause in their workout with instructor Susie O'Donnell.

pool irritate the eyes. While this is not harmful, it is annoying. More importantly, goggles help get the students past a major hurdle in learning to swim — immersing the face in the water. Few swimming strokes can be swum properly or efficiently without most of the weight of the head being supported by the water. With front strokes (front crawl and breast stroke), the face is immersed throughout most of the stroke. Until the student learns to swim with his face submerged and to breathe rhythmically, progress in these important strokes will be quite limited.

One typical fear that keeps children from putting their faces in the water is reluctance to get water in their eyes. I suspect this develops from getting soapy water, which stings, in their eyes during baths. By wearing goggles, the students realize that they can see well under water and that their eyes are protected.

Children with spina bifida can become excellent swimmers of the front crawl, which gets little propulsion from the legs. However, they have difficulties with the back crawl, since their legs often float up into a jackknife position when they are on their backs. The breast stroke is not very effective for any student with limited leg mobility.

Often, individual adaptations must be worked out for students with cerebral palsy. If necessary, we will let such students swim with floats attached to

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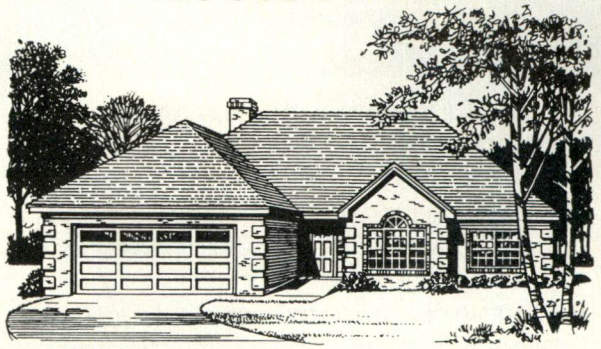

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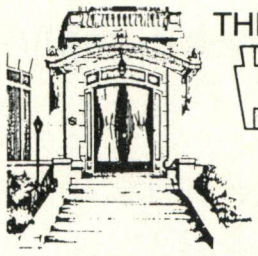

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their bodies, either inflated arm cuffs or styrofoam floats taped to their ankles. However, every effort is made to eliminate such aids as soon as possible. One reason is that reliance on swim aids does not prepare the students for survival of an accidental immersion, one principle goal of the program.

Students with visual impairments can often be taught the strokes by physically guiding their arms and legs through the proper motions. In this case, the pace of instruction must be adapted, not only to the learning ability of the student, but also to the student's degree of hesitancy towards new experiences. We always bear in mind that we are dealing with children who may have had few successes in dealing with the physical world.

WHERE TO BEGIN

Parents who wish to find a swimming program for their child might start by inquiring at the local American Red Cross office. School officials involved in special education programs and people active in local swimming instruction programs might also know of available programs.

If there are no convenient swimming programs, parents may want to consider starting a program in their community. The Red Cross can give invaluable help. "Water time" (scheduled use of a municipal pool) will be needed. An indoor pool is recommended, as a summer-only program would be of limited value. Water time is expensive, so fees will probably be necessary.

Recruiting dedicated, dependable instructors can be the biggest hurdle. The volunteer whose attendance is sporadic is of limited value, no matter how inspired his teaching. For teaching beginning swimmers, the instructor's skill is less important than his patience and sincere desire to teach.

Dedicated teachers should be encouraged to move through the Red Cross swimming instructors programs. Advanced training will make instructors more useful and make their work more personally satisfying. The Instructor's Course in Adapted Aquatics is a course specifically intended for teaching swimmers with disabilities. However, other courses must be taken first. The Advanced Lifesaving course is a prerequisite for being certified as a Water Safety Instructor, which is a prerequisite for the Adapted Aquatics Instructor course.

Robert F. Bond is the coordinator of the North Jeffco Recreation District Handicap Swimming Program. He is an American Red Cross certified Water Safety and Adapted Aquatics Instructor. Retired from his position as an international marketing services manager, Bond lives in Golden, Colo., with his wife, Mary, and works as a freelance writer.

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PROPER SEATING:
A Key to Participation

Children need to be able to sit upright in a stable position and move about in the world in order to participate in the everyday activities of growing up. For many young children with severe physical disabilities, therapeutically designed and prescribed seating systems can make a dramatic difference at home, at school and in the community. In this article, guidelines for under-standing seating options for infants and pre-school children will be presented to help readers work actively with therapists to meet the needs of their children.

The seated position is just one of the many "positions" in a child's everyday life. Seating deserves particular attention because so many social and educational activities are done sitting down. However, as important as proper seating is, parents and professionals always need to keep the overall goals for the child in mind and remember that proper seating does not eliminate the need for therapies or the need to be comfortable in other positions. The goals of proper seating are to enable a child to take part in the same activities that his peers and family members enjoy as well as to be able to participate more actively in special programs designed to meet special needs.

When a child is properly seated, he or she will be better able to use both hands and concentrate on the activity itself rather than be worried about balance and personal injury. For example, many families enjoy playing board games while seated around a table. With proper seating, a child is likely to have better control of the arm and hand movements necessary to participate in Candyland, checkers, Monopoly and many other popular board games.

For a thorough discussion of positioning, see Elaine Trefler's article, "Positioning: Concepts and Technology," EXCEPTIONAL PARENT, July/August 1988, pp. 28-33.

COMPREHENSIVE ASSESSMENT

A careful assessment of a child's specific needs by parents and clinical team members is essential in order to identify all seating options. In this collaborative effort, parents and team members need to discuss the different environments (family room, bedroom, kitchen, bathroom, school rooms, automobiles and outdoors) where the child sits (or lies) so that in each place the child can be as actively involved in family or community life as possible. Then the parent/professional team can develop specific recommendations for each environment with consideration of whether the child can use: (1) standard furniture with adaptations; (2) specialized commercially available equipment; (3) specialized equipment customized to meet the unique needs of the child; or (4) completely customized, individually prescribed seating system.

From early in life, children sit at different heights in different places. For some children, one seating system may be fine for a number of different settings. For others, each situation may require modifications.

In determining the best seating for an individual child, comfort and safety are key criteria. In addition, whenever possible, the seating should facilitate the development of existing muscle strength and/or coordination, as well as protect the child from injuries caused by sliding out of the chair or from pressure sores (*decubitis ulcers* is the technical term).

Many children need only firm back support and a firm seat bottom. Usually, the back support and seat are

C.A.M.P. Photo

mounted at approximately 90 degrees. Such seating provides comfort and support and prevents the child from slouching or slipping into inappropriate positions. In addition, a seat belt is an important part of most seating systems because seat belts provide additional support to help the child maintain proper posture as well as protecting the child from injury.

Depending on a child's ability to control his head and neck, a higher seat back or special neck and head supports may be needed. The team can also discuss whether arm rests will be helpful and/or whether a lapboard or wheelchair tray is needed for various activities.

Finally, since many activities can be enjoyed while on the floor, on a couch or bed lying on the stomach (called *prone position*) or on the back (called *supine position*), the team also needs to review the most appropriate positions on the floor or bed as well as the best supports in each place so that a child can interact effectively.

BUYING DECISIONS

Today, because an increasingly wide range of well designed products are commercially available (and often reimburseable via health insurance programs), the creation of completely customized systems may not be necessary. However, experts who can help determine the individual eating and positioning needs of a child with severe physical disabilities may not be readily available in all areas. (For information about trained experts in your community, see note at end of article.)

Once decisions have been made to purchase special equipment, it is best to try before buying. Ordinarily, before the team prescribes a specific system, a child sits in the system so that parents and team members can observe and try various modifications that may be needed. In addition, as part of the purchasing decision process, parents can ask therapists or parent organizations to identify other parents whose children use same or similar equipment.

INFANCY

Babies, as well as children of all ages, enjoy playing on the floor. Cushions or specially designed foam pillows or wedges (different shapes) can be used to provide support so that a child who is unable to support himself can play on the floor. Other special devices such as *prone positioners* (specially designed wedge-shaped equipment, made of wood, plastic or foam and equipped with straps, cushions or other materials; often called *prone boards*) may be advisable for a child to use while lying on his stomach.

For sitting, plastic baby seats usually do not provide enough support for the child with physical

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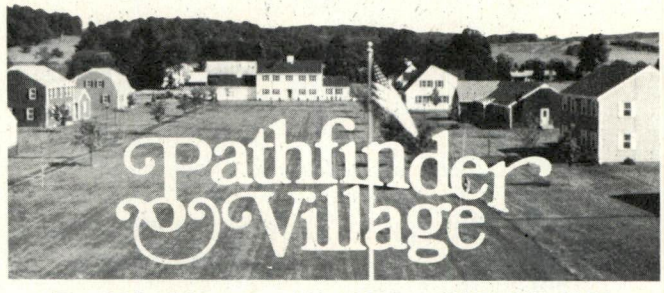

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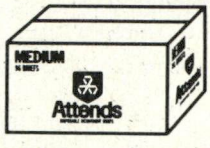

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disabilities. There are now a number of specially designed seating systems (that may also fit in strollers or wheelchairs) which are excellent. Sometimes, an individual child may need additional foam padding or wedges to use with the seating system as he or she grows. For eating, sturdier high chairs may be sufficient with some foam modification or the seating system itself may be attached to the highchair.

For getting around in the home or outside, parents can consider specially designed strollers that provide proper support or the use of special inserts (seating system) in ordinary strollers. Because federal safety standards for child restraint systems for automobile travel apply only to youngsters who weigh 50 pounds or less and are not disabled, it is essential to consult with the clinical team when working out details of car travel.

For a more complete report on the subject, consult J.D. Stout, M.J. Bull and K.B. Stroup, "Safe Transportation for Children with Disabilities," *American Journal of Occupational Therapy*, January 1989.

PRE-SCHOOL YEARS

At this age, because children begin to do many things outside of the home, a careful assessment of each setting is essential. For example, in reference to mobility, if the child enjoys accompanying parents on shopping excursions, a stroller may be best. However, if child attends a school program and is transported via bus, then strollers are usually not strong enough for bus safety.

At home and in community programs, children are now participating in many activities seated at play tables. For some children, regular classroom furniture with slight modifications will be sufficient. For others, customized systems may be needed. Since many new wheelchairs come with adjustable seat heights, the most effective approach ordinarily is to move the wheelchair to the table or desk.

Once a child is mobile via a wheelchair, stroller, or walker, the entire home needs to be accessible so that a child does not need to be carried from place to place. For meals, if the mobility device can get into the kitchen but cannot be pulled to the table at proper height, the child will need to be able to transfer to a seat at the table or use a sturdy tray table on the wheelchair to eat while remaining in the wheelchair.

Children with physical disabilities are usually ready for toilet training at about the same time as other children. However, when a child has difficulty with seating balance, toilet training is often needlessly delayed even though the child is developmentally ready. This is particularly unfortunate because using the toilet independently to ensure privacy will become an important issue when the child is older.

Small children can use special potty seats on the floor that provide support and enable the child's feet

to be on the ground. For some children it may be necessary to construct a box-like seat around a standard potty chair to provide safe support. As child gets older, specially designed toilet seats that clip onto or fit over a toilet or are attached to walls (grab bars, rails) can be very helpful. There are also products available for bathing which provide support in the bathtub or shower.

For mobility, besides wheelchairs and strollers, preschool children may use scooter boards, caster carts, walkers, and/or crutches. The major issue in selection is whether the child be independent in the community with this equipment. Accordingly, for the child who needs a wheelchair, can the child move the chair by himself without undue physical exertion so that he has energy remaining for participation in the activity when he gets there? Once a child is 3-5 years of age, it is time to consider powered mobility especially if child is unable to or unlikely to be able to propel a standard wheelchair independently.

—S.D.K.—

Our special thanks to Elaine Trefler, O.T.R., M.Ed., Assistant Professor of Rehabilitation Engineering and Director of Education at the Rehabilitation Engineering Program at the University of Tennessee/Memphis Health Science Center, who was a resource person for this article.

REFERENCE NOTE

RESNA (an interdisciplinary association for the advancement of rehabilitation and assistive technologies) has a special interest group on "Wheeled Mobility and Seating." The chair and vice chair of this group can be contacted to suggest trained professionals thoughout the country:

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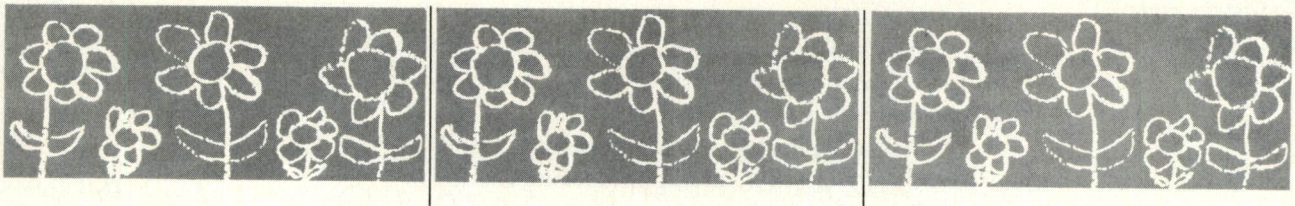

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A Camping

By insisting on mainstreaming, parents and children can teach others.

By
Kate Divine
McAnaney

"Let's see . . . power chair, manual chair, battery charger, tire pump, pliers, bike buddy, tray, emergency numbers, asthma inhaler, medical card. And . . . sleeping bag, pillow, pants . . . more pants, underwear, pjs, shirts, coat. There! I think that will do it!"

Our 11-year-old son, Mahlon, is off to science camp, the outdoor education program offered to all fifth graders in our county. It's an opportunity to experience the great outdoors and learn about nature. It's an opportunity to be away from home and have fun. It's an opportunity to learn to live with your peers.

And, for us, it's yet another opportunity to educate another small population on how to Accept, Accommodate and Enjoy a child with special needs. This is an "Adventure Package" that we have "offered" frequently over our years as parents of a physically-challenged child. Mahlon was a premature baby, and by the time he was eight months old, it was evident that he had cerebral palsy. His major impairment involves motor skills, so he needs a wheelchair and total assistance with personal care. However, he has always been mainstreamed and can keep up with grade-level work.

ACCEPT, ACCOMMODATE, ENJOY

The Accept part of the package is unavoidable. We expect our son to be mainstreamed whenever possible: in his school, in our neighborhood, in social activities. After all, he's a "regular kid" in a wheelchair.

I wave good-bye to Mahlon amidst all the other nervous and excited campers as I pull away in my van.

The Accommodate portion of the package is often an inspiring revelation for participants as they call upon their own resources (inner and outer) to solve problems: resources they were unaware they had. I have often gotten great new ideas from people who could look at my situation with Mahlon from a fresh perspective. I love new ideas!

The best part of this Adventure is the Enjoy part. Exceptional children give back so much with their unique point of view and their unconditional love that everyone comes away enriched. Mahlon's toileting aides thanked me at the end of the school year for the "privilege of helping Mahlon." And they were just taking him to the bathroom!

OUR CHILDREN: OUR GIFT TO THE COMMUNITY

Allowing our exceptional children to be mainstreamed is a gift to the community, whether it be Cub Scouts, Brownies, the schools, the church, or the neighborhood. Insisting on mainstreaming (if you've decided it's appropriate) is often a lonely road. We face reluctant administrators, hesitant teachers, classmates, parents, doctors, dentists and a whole parade of uninformed and often scared citizenry. It's not a fun task. It's frustrating, confusing, exasperating, thankless and exhausting. But it can be worthwhile.

Mahlon called the second night he was at camp. "Dad, I need to come home." My husband had an initial moment of panic: Was Mahlon hurt? Was he being ignored? Was he being made fun of? He then calmly determined that it was none of

We Will Go . . .

Michael, 10, helps his brother, Mahlon, 12, prepare for camp.

these things. Mahlon, like many other campers, was just homesick. We encouraged him to "hang in there" for at least another day, even though he was now dependent on near strangers for all his needs. He did "hang in." He stayed the rest of the week and never regretted it.

WE ARE TEACHERS

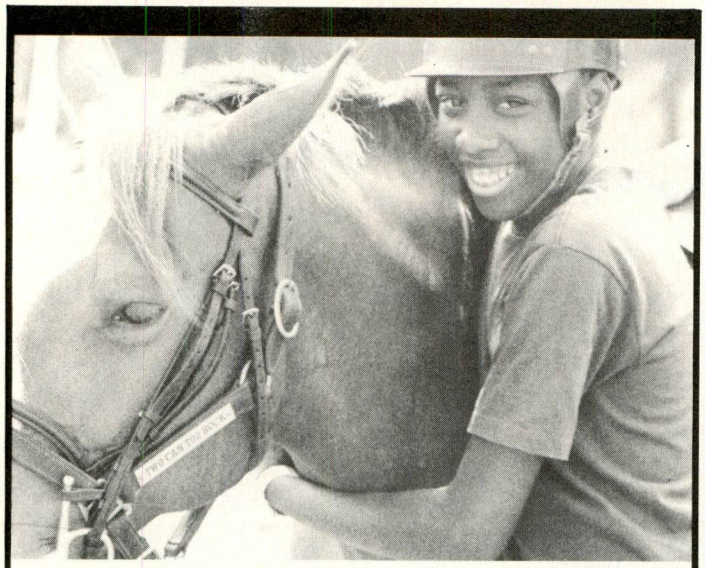
We have to adopt the attitude that we and our children are teachers and that we have some valuable information to offer. We can "teach" things that people need to know: how to accept people with disabilities, how to "help," how to be flexible (this is a biggie!), and how to "go with the flow." I have learned this!

I cannot count the times that our plans have come to an abrupt halt because Mahlon's wheelchair has a flat tire, a blown fuse, a dead battery, or a broken belt. We quickly readjust and fix it or find an alternative. People without physically-challenged children can help out at these times too, and when they find a solution for you, they feel great about it! We just have to offer people the opportunity to help.

MAINSTREAMING: MY RESPONSIBILITY, TOO

I take my role as "educator" seriously, recognizing that the success of mainstreaming my son is my responsibility too. Just because there are laws in place that say it should happen, is no guarantee that it will be done effectively, smoothly, or that it will be an enriching experience for your child.

Whenever I plunge into a new situation — new school, new neighborhood, new class, or new experience (like science camp) — I assume the people I'm working with know nothing. I like this assumption because it means I can start from square one. I can give them complete and accurate



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information and hopefully overcome any preconceived ideas about Mahlon in particular and about people with special needs in general. I can undo prejudices or at least set the stage for dissolving those prejudices.

I begin my process by telling people about cerebral palsy. Each year, from kindergarten and up, I've gone to Mahlon's class and given "our talk" during the first week of school. We, Mahlon and I, talk about what cerebral palsy is, why Mahlon has it, why he is in a wheelchair, what he can do, and what he can't do — emphasizing that you "can't catch" what Mahlon has.

I take along visual aids to illustrate prematurity. We have a regular size baby doll and a preemie size doll. We have the doll clothes Mahlon wore in the intensive care nursery. And we have foot and hand prints of Mahlon and his brother at birth (his brother weighed 10 pounds at birth; Mahlon weighed two pounds). I know I can get the kids' attention with this approach. Then I give them the information. I give them the "big" words: cerebral palsy, brain injury, ventilator, physically challenged.

And we talk about how everyone has challenges, i.e., something that's hard for you to do. "For Mahlon it's hard to write and hard to move like you do. For you, maybe math is a challenge, or spelling, or reading, or playing the piano."

Children are wonderful. They listen and they understand because they are eager to know why Mahlon is in that fantastic motorized chair!

After I've taken care of the "whats" and the "whys" of my teaching process, I go to work on the "hows:" How will he get from here to the library? To the bathroom? To the cafeteria? How will he write his assignments? How will he go on field trips? And how will he go to science camp?!

My second great assumption is that any "how" question has an answer. If I'm absolutely backed into a corner, I'll say "I don't know about that one . . . but I'll figure out something!"

One parent lamented to me that it was "too bad about science camp," presuming, of course, that Mahlon couldn't possibly attend. Others may have had the same presumption.

I could hear opportunity knocking! I called the camp director and said, in an engaging voice, "Hi! I have a son with cerebral palsy who uses a wheelchair to move around and he's in the fifth grade at Robert Down School and will be attending camp the week of May 23rd. I'd like to meet with you and your staff so we can work out the details."

POSITIVE, PATIENT, PERSISTENT

I'm Positive, Patient and Persistent and ready for the tough questions. Maybe I have just been lucky, but I have found that when I give people the opportunity

to help, they usually do. If I approach mainstreaming with a positive attitude, I often find willing supporters. I may have to give them on-the-job training, but that's fun! Even the most reluctant folks can be inspired and can reinspire me!

The camp director was definitely reluctant. "How will he go hiking? We do lots of hiking you know."

"No problem!" I replied. We, as a family, worked out the answer to this one long ago. We also do a lot of hiking. We found that the pull-along child carrier we had purchased for my bike worked splendidly as a "rickshaw" to pull along the trails.

My husband got a wide army belt, hooked the arm of the "bike buddy" to the belt, fastened it around his waist and announced "I think this is going to work!" It did, and it has — for years. We use it at the ocean to run along and chase waves, in pledge runs, and in any rough terrain where his wheelchair won't go. So we sent it to science camp. The counselors loved it! It broke up the monotony of just another week at camp.

Mahlon's classroom teacher jogged up along side Mahlon's rickshaw as they were hiking one day and asked how camp was going for him. Mahlon answered brightly, "Just great!" And then added with a twinkle, "Except I can't get my slaves to go fast enough!"

And so science camp worked. And school thus far has worked. YMCA Indian Guides worked. Swim lessons worked. And next year we face middle school, and after that high school, then college — new people, new systems. New problems, new solutions.

I didn't imagine parenting would be like this, but it is, for me — for us. And even in those times of utter weariness and deepest discouragement, I know my efforts are worthwhile. Mainstreaming is important.

There will always be people who think I'm too assertive; there will always be doctors, teachers and therapists who don't appreciate my input; there will always be people who don't want to learn about special needs. But if I can — if *you* can — help people to realize that mainstreaming can be a positive opportunity for children and adults, then all the frustration is worth it.

Kate Divine McAnaney is the regional coordinator for United Cerebral Palsy of Monterey and Santa Cruz Counties, Calif. She is a graduate of the University of California—Davis, and a board member of the Carmel Valley Youth Center. She lives in Carmel Valley, Calif., with her husband Patrick and their two sons, Mahlon, 12, and Michael, 10.

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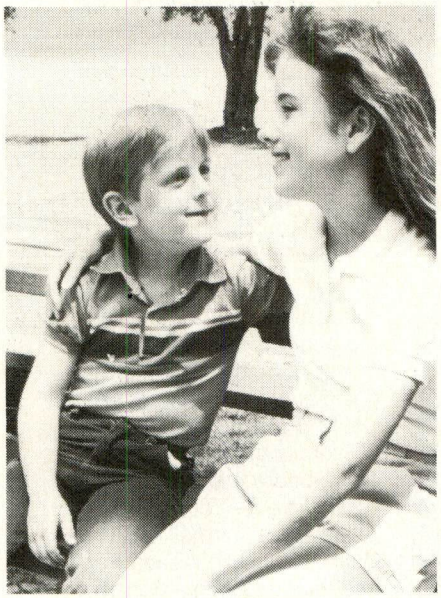

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WHAT'S HAPPENING

PARENT ACTION

The Family Resource Coalition (FRC), a national organization whose goal is to improve the quality and expand the number of programs available to families, has announced a new division called PARENT ACTION, a national advocacy organization that promotes the issues and concerns of families.

Professionals are welcome to join parents in this advocacy effort. Membership is $5.00 for one year, and a combined membership in PARENT ACTION and FRC is $20.00. For more information, contact PARENT ACTION, 230 N. MichiganAve., Suite 1625, Chicago, Ill. 60601, (312) 726-4750.

EARLY INTERVENTION ADVOCACY NETWORK

The Early Intervention Advocacy Network is a project of the Mental Health Law Project (MHLP), a highly-respected Washington-based public interest group that advocates for the rights of children and adults who have developmental disabilities. MHLP has concentrated its advocacy efforts on test-case litigation, policy advocacy, and educational outreach and has made significant differences in the lives of persons with developmental disabilities.

MHLP began the Early Intervention Advocacy Network in response to the passage of Public Law 99-457's Infant and Toddler Program. Participants in the Network regularly receive updates on implementation of 99-457 and "Alerts," periodic communications about upcoming events, such as public hearings on state applications for Infant-Toddler Program funds.

Participation in the Early Intervention Advocacy Network is free of charge. For more information, contact Margaret Lorber or Beth Carter at MHLP, 2021 L Street, NW, Suite 800, Washington, D.C. 20036, (202) 467-4730.

NETWORKING WITH TECHNOLOGY

SpeciaLink is a high-tech social service agency whose purpose is to encourage, advance, and enhance the use of computers in the daily lives of persons with physical, intellectual, and/or emotional disabilities. The goals of SpeciaLink are to increase understanding of how computers can benefit individuals with special needs, broaden the awareness within the community of the different uses of computers and related technology and to increase the implementation of microcomputer technology for children and adults with disabilities.

SpeciaLink is a member of the National Special Education Alliance, a grass-roots network of resource centers for people with disabilities. SpeciaLink published a monthly newsletter ($10.00/year), has developed an electronic data base of vendors of adaptive hardware and software, and has established a center allowing people to try both software and hardware before purchasing it.

For additional information, contact Elaine or Wally Hackett, P.O. Box 12750, Cincinnati, Ohio 45212, (513) 351-8519.

NATIONAL FEDERATION OF THE BLIND SCHOLARSHIPS

In recent years, the National Federation of the Blind has devoted substantial effort and resources to its scholarship program. This has been done in the belief that if the blind are to achieve first-class status in society, they must have the opportunity to compete with others on terms of equality. This is another way of saying that the blind must be able to attend institutions of higher learning. To that end they continue to strengthen their scholarship program.

In 1989, twenty-six outstanding blind students will receive scholarships from the Federation, totaling $69,000 in cash plus payment

of their expenses to the National Federation of the Blind convention in Denver during early July. Ten blind scholars will receive awards of $1,800; two will receive awards of $2,000; ten will receive awards of $2,500; three will receive awards of $4,000; and one (the student judged to be the most outstanding blind scholar in the nation) will receive a $10,000 scholarship award.

The scholarship application form will be sent to every college and university in the country, every agency doing work with the blind, every congressional office, every NFB state president, and every member of the Scholarship Committee. They will also be sent to anyone requesting them. These are worthwhile scholarships, which will be of real assistance to blind students.

To receive forms or to obtain further information, contact Peggy Pinder, Chairman, National Federation of the Blind Scholarship Committee, 814 4th Avenue, Suite 200, Grinnell, Iowa 50112; phone (515) 236-3366. Forms can also be had by writing to: Scholarships, National Federation of the Blind, 1800 Johnson Street, Baltimore, Maryland 21230. Forms must be received by March 31, 1989.

NATIONAL LD HOT LINE

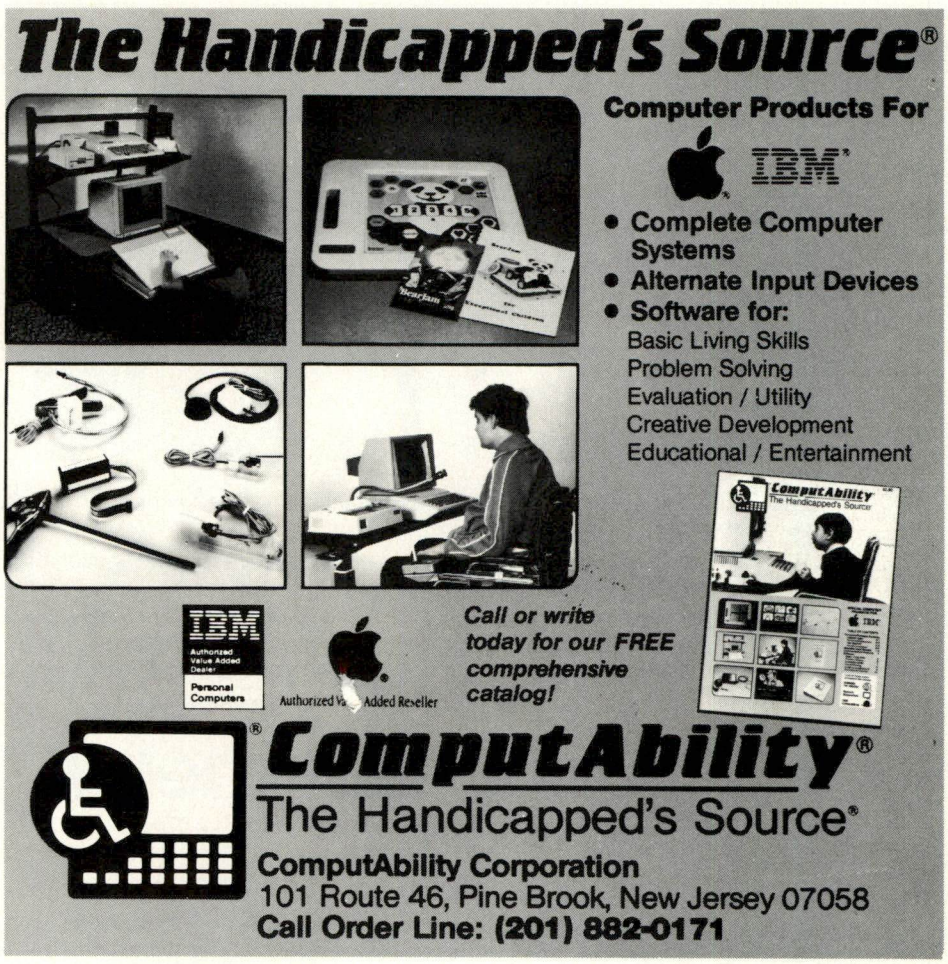
The Learning Disability College Unit of the University of Connecticut has announced the establishment of a national 24-hour hot line which will provide assistance and support services free of charge for LD service providers and college students with learning disabilities. This hot line has been developed as part of the new "National Center on Postsecondary Transition for Students with Learning Disabilities," which will be housed in the Special Education Center at the University. Among the services provided by highly qualified staff are the dissemination of relevant current publications and information on programming alternatives, support to postsecondary administrators, counselors, and related student support staff and a national newsletter, "Postsecondary LD Network News," which includes the latest information on conferences, resources, and "best practices" for service providers.

The Center is designed to ease the transition from high school to any postsecondary setting so that young adults with learning disabilities can reach their maximum potential. For additional information, or questions about LD post-secondary transition issues, call (203) 486-4036.

PARENT TO PARENT NATIONAL SURVEY PROJECT

Parents caring for a child who has a disability often find that their best resources are other parents who have been there and understand firsthand their feelings and their experiences. Since the 1970's, Parent to Parent programs around the country have responded to these needs by pairing "veteran" parents who have successfully handled many of the challenges present in families who have a child with a disability with parents who have recently learned of their child's disability. In these programs, often called "Parent to Parent," "Pilot Parents," "Parents Helping Parents," or "Parents Reaching Out," experienced parents offer emotional and informational support to referred parents through this match.

In order to find out more about the way Parent to Parent programs operate and what makes them successful, the Parent to Parent National Survey Project at the Beach Center on Families and Disability at the University of Kansas, is conducting a national survey of parent support groups that use the parent to parent approach. As this information is compiled and made available to families and



professionals, the Beach Center staff hopes that it will be useful in the development of a national Parent to Parent Network that can help programs learn from each other and assist new groups with start-up tasks.

Programs that use the parent to parent approach are encouraged to call or send a postcard with the name, address and telephone number of a program representative by April 30, 1989, to Betsy Santelli, Project Coordinator or Ann Turnbull, Co-Director for the Beach Center. Reply to: Parent to Parent National Survey Project, Beach Center on Families and Disability, Bureau of Child Research, 4138 Haworth Hall, University of Kansas, Lawrence, Kansas 66045-2330, (913) 864-4950.

A positive response will enable participants to find out about and share materials with other Parent to Parent groups, be included in the development of a national Parent to Parent Network, discover the characteristics of Parent to Parent programs that lead to successful programs, and learn about training and technical assistance opportunities.

We are pleased to be working with EXCEPTIONAL PARENT magazine. We look forward to reporting the results of our work in EXCEPTIONAL PARENT.

WHEELCHAIR TENNIS

There is a tremendous need throughout the country for organized sports and recreation of physically disabled youth. In an effort to satisfy this need the National Foundation of Wheelchair Tennis (NFWT) has created the Junior Wheelchair Sports Camp Program.

In 1981, the NFWT focused its attention on developing programs for physically disabled youth: the future of wheelchair tennis. A camp style program was created. The program provides physically disabled youth the opportunity to enjoy the benefits and rewards associated with sports and recreation.

The first Junior Wheelchair Sports Camp was held in 1981, offered free of charge to youth between the ages of seven and 18 and provided instruction in various sports (tennis, archery, basketball, physical conditioning, track & field and aquatics) by physically disabled athletes who serve as role models for the campers. The overwhelming success of the first camp has led to the development of additional programs in other areas.

The following is a schedule of camp programs available across the country. If you have any questions, please contact the National Foundation of Wheelchair Tennis, 940 Calle Amanecer, Suite B, San Clemente, Calif. 92672, (714) 361-6811.

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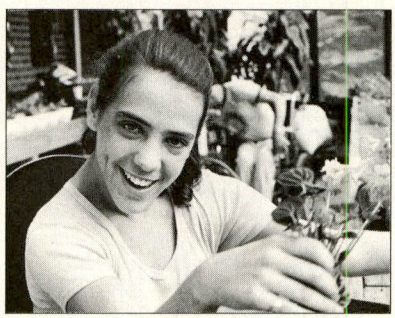

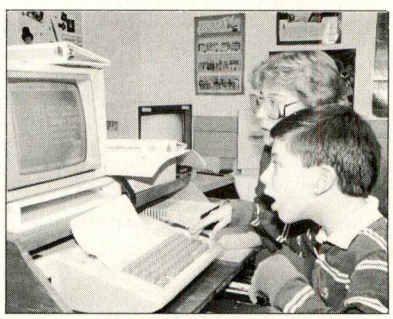

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Contact: Dr. Nick Breit
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June 26 - June 30

Pomona
Casa Colina Hospital and Rehabilitation
Contact: Jim Miller
(714) 593-7521, ext. 412
July 26 - July 29

Santa Barbara
University of California at Santa Barbara
Contact: Bill Hamilton
(805) 962-1474
August 22 - August 26

COLORADO

Englewood
Cherry Creek High School
Contact: Beth Nyhoff
(303) 694-3142
June 12 - June 16

FLORIDA

Sorrento
Easter Seal Society
Contact: Shana Stearn
(904) 383-4711
Date to be announced

ILLINOIS

Champaign
University of Illinois
Contact: Brad Hedrick
(217) 333-4606
July 2 - July 9

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Grand Valley College
Contact: Jennifer Knight
(616) 242-0454
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Contact: Kathy Feuillan
(713) 643-7366
Nancy Meade
(713) 855-2246
Date to be announced

CORRECTION: SSI REVISIONS

In the November/December 1988 EXCEPTIONAL PARENT, in our What's Happening column, we ran an article entitled, "SSI (Supplemental Security Income) Revisions." The last sentence stated, "For more information, contact your local SSI office." This is incorrect.

The Social Security Administration (SSA) administers the SSI Program under Title XVI of the Social Security Act. Therefore, any and all matters concerning the SSI program must be handled through your local Social Security office. There is no such thing as an SSI office per se, and our readers could possibly be misled by this statement.

We would like to thank Layne M. Herber, District Manager of the Social Security Administration in Billings, Montana for sending us this clarificiation.

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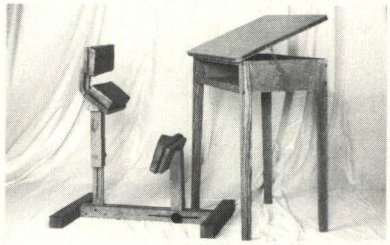

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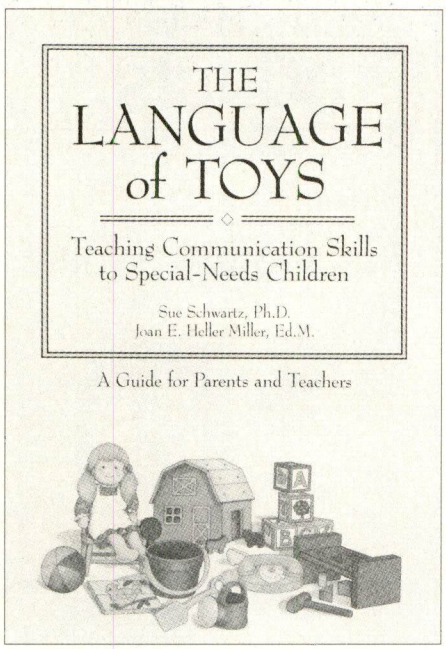

The Language of Toys: Teaching Communication Skills to Special-Needs Children - A Guide for Parents and Teachers

by Sue Schartz, Ph.D. &
Joan E. Heller Miller, Ed.M.

The following excerpt has been reprinted with permission from the publisher, Woodbine House, Inc.

Developing communication is as much a basic human need as seeking food and comfort. For many children this is a relatively simple process, while for others there may be significantly delays in this area. There are a wide variety of causes for a language delay in this area. Regardless of the cause, the results are usually the same: a child with delayed language development and concerned parents.

These concerned parents want to help their children with special needs learn language skills but often don't know the best way to go about it. Through our years of teaching and raising our own children, we have seen that an amazing amount of language can be pulled from even the simplest toy. Our book, *The Language of Toys*, shows you how to use toys to aid your child's language development. While you are playing with your child, you can be helping him increase his language skills. And you can have fun together at the same time. We know your child can benefit from these times with Mom and Dad. We also know this play/work time is dramatically more important for children with delays in their language development. They will need the extra effort that their parents can give them to help develop their language skills.

When speech and language therapists or teachers work with children with language delays, they usually use toys they think will encourage certain words or sounds. There is no "magic" to the toys they use. Rather, the toys are chosen carefully to be teaching aids. This book will help you to choose and to use toys like the professionals to enhance the development of language in your child. Although we have selected certain toys for this book, we want to assure you that there are many other toys that can be bought or made which can serve equally well.

The Language Of Toys is divided into two parts. In the first part, we explain important background information about language, its sequential development, some of the causes of language delay, the value of play, how play can enhance language development, and your role in all this. In the next section — which is the heart of the book — we recommend toys that we have found to be useful in stimulating language development and show you how to use these toys in playing with your child. For each toy in the book we provide you with sample language dialogues to help you get the most from that toy. We encourage you to use these ideas in your play to encourage language development.

We have designed this book to be used with any child who has a language delay, whatever the cause may be. We have given you guidelines which should help you decide which toys your child would be most interested in playing with and most ready to learn from. These guidelines are based on language developmental ages. Each child has his own unique profile for all developmental areas, including cognition, motor, social, self-help, and language. A child may make progress in different areas at different rates. The result is wide variation in the developmental picture for each child, regardless of his chronological age. For example, a three-year-old child with a twelve month language delay may have "normal" cognitive development or motor skills but speak on a two-year-old level. Alternately, a four-year-old child with "normal" language may have very delayed motor skills.

We have individual suggestions for modifying your play to accommodate the specific learning needs of each child. We are sure that we haven't addressed every individual need but we feel that you will be able to adapt our suggestions to your own child. The toys and exercises in this book are arranged by language developmental ages. Each section covers several months and presents toys and dialogues that are appropriate for your child's particular level of language development. There are similar guidelines throughout the book to help you pick toys that are the most appropriate for your child's level of language development.

In addition to toys you can buy, we also include at least two homemade toys for each of our language development levels. Many people enjoy making toys and there is a lot of benefit — including saving money — in this. In our work, we have found that children and parents treasure these homemade toys long after other toys have been packed away.

Remember, our suggestions are only suggestions. Expand and create. There are many books in libraries and in bookstores which will tell you more about homemade toys. We have included several in

our reference list at the back of this book.

Parents often ask, "When should we start?" You can start the exercises in this book even before your child's language delay has been formally diagnosed. If you already know that your child has some special needs, you have to consider the possibility that he is language delayed too.

Do not wait until you have a specific diagnosis of language delay to begin. Often your child's diagnosis has to wait until you are able to test him and in many cases that doesn't happen before age two. You can always work on his language skills even before getting a diagnosis. It can only help him in the long run.

As you will see in our chapter on language development, you would not expect your child to be talking in understandable language much before one year of age. We want you to enrich your child's language long before that time.

If your child is an older preschooler and you have just gotten the diagnosis of a language delay, then you can start this book at whatever level your child is placed and work from there. You might even be working with a therapist or school at this time. Show them this book and explain how you want to integrate our ideas with your child's specific plan. You will probably find that our examples fit right in with your child's individual education plan.

We do not expect, or want, you to turn into a teacher for your child or to lose your role of parent. However, you can combine both roles in a way that is fun for both you and your child. There is also no need to occupy your child's every waking moment with the exercises in this book. There at times when children should play alone because that is when they build independence and develop imagination. We believe, however, that parents, teachers, families, babysitters, and others can enhance the development of richer language by playing with toys with children for part of the child's playtime.

Follow your child's lead. If he is interested in farm animals, explore that area in your play. If you see that he has no interest at all in cars and trucks, then put that idea aside for a while. Your play should be fun, interesting, and meaningful. Experience your childhood again and enjoy the time you will spend in playful learning with your child.

Copies of ***The Language of Toys*** *may be purchased through the Exceptional Parent Library at $12.95 per copy, plus postage and handling,* *see page 75.*

Dear Mom and Dad.
Today I went to the
Special Olympics and
I won a medal.
Love,
Joe

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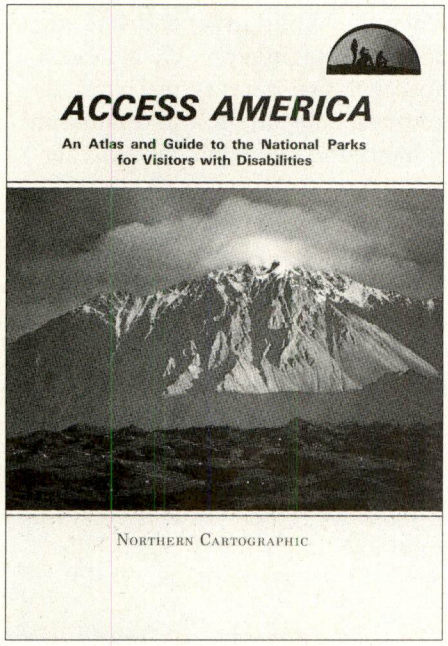

Access America: An Atlas and Guide to the National Parks for Visitors with Disabilities by Northern Cartographic, First Edition

The following excerpt has been reprinted with permission from the publisher, Northern Cartographic, Inc.

Most maps and guidebooks of parks are just that — one-dimensional catalogues of information designed to orient the reader to a particular outdoor space or feature. In stark contrast, *Access America: An Atlas and Guide to the National Parks for Visitors with Disabilities*, is the antithesis of the traditional guidebook.

Access America represents the most multi-dimensional attempt to make the parks not only accessible, but usable, to people who represent the full spectrum of human abilities. Because of the variety and depth of information provided, the prolific use of maps and other graphics, and the addition of a genuine human element (through the inclusion of a series of personal essays), the readers is taken on a multi-faceted journey.

Outdoor recreation experiences are among the best that life has to offer. Nothing seems to refresh me more than being outside in the natural environment. Although I enjoy a wide range of activities, the adventure of outdoor experiences always gives me a new perspective on my routines.

Unfortunately, the potential "adventure" can easily turn into frustration and exclusion. Many outdoor experiences are simply not as available to persons with disabilities as they are to non-disabled persons. Many times I, and others with disabilities, have set off to explore and enjoy a park only to be confronted by a myriad of barriers.

In some cases unavailability is compounded by the lack of reliable information. For example, I have telephoned sites or read guides that have labeled places "accessible", only to find when I arrived,that there were accessible parking spaces or an accessible toilet, but no way to enter the nature center or picnic area or campground, nothing available in large print, and no telecommunication devices for deaf persons.

The authors of *Access America* have demonstrated a remarkable awareness and understanding of the difficulties, both natural and man-made, faced by persons with disabilities. The final product is a testament to the rigorous process, including extensive surveys and site visits, employed to develop this book and the many years that went into its production.

It is often said that too many cooks can spoil the broth. In this case the use of nearly sixty consulting editors, many of whom are persons with disabilities, certainly enriched the broth. From my perspective, having been involved in many projects using editorial boards, I think having sixty advisors was a brave feat in itself!

Reading this book as both a person with a disability and as the Executive Director of the National

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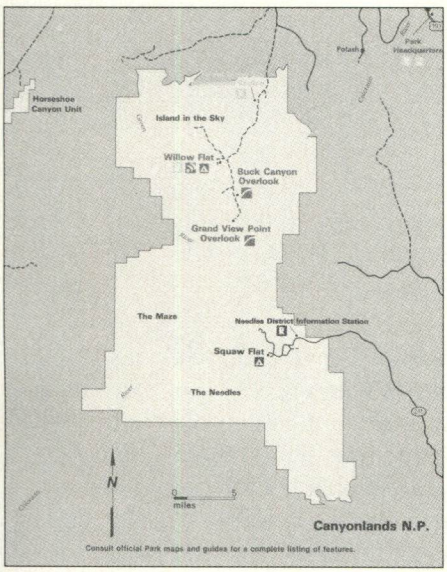
Council on the Handicapped, it is my view that the contribution made by *Access America* is broad and far-reaching. *Access America* reinforces two major themes currently emerging from the disability



movement — independent living and equal opportunity. The essence of independent living involves people with disabilities making their own decisions and being involved in every aspect of life. Frequently, recreation choices have been ignored or given a low priority. Access America will enable persons with disabilities to make their own choices about which parks to visit and which experiences within those parks they select.

Evidence of equal opportunity is also apparent. Equal opportunity for persons with disabilities means having the same access to opportunities as non-disabled persons and not being discriminated against because of an individual's disability. By virtue of the fact that a book on accessibility exists to describe what is accessible and what is not accessible implies that opportunities are not equal.

However, movement toward equal opportunity has occurred. Fifteen years ago, the majority of accessible features described in *Access America* did not exist. The fact that progress has been made means that persons with disabilities have gained and are continuing to gain access to more opportunities.

I believe that all Americans, whether disabled or not, have the right to experience recreation and have access to recreation facilities and spaces. I commend the National Park Service for its initiatives to make the out-of-doors accessible to persons with disabilities.

I applaud the effort of Northern Cartographic, Inc. to create a resource that will greatly enhance the outdoor recreation experiences of persons with disabilities and their families and friends. The interest, curiosity, and commitment demonstrated by the authors are exemplary.

It was my pleasure for me to provide a foreword to such an historic document. My wish is that so much progress will be made each year that supplements will be needed to provide information about new and better accessible features.

Park visitors with disabilities must use this book not as the final step in their research and planning of a visit, but as a good first step — a first step that leads to questions and follow-up at the level of the local park. If the atlas accompanies the visitor to the park, it should not be used as the exclusive source of accessibility information but as a basis of further inquiry to confirm, clarify and particularize every situation.

Changes occur and mistakes get made; there is no substitute for vigilance. Through correspondence, telephone calls and on-the-spot interrogation of National Park Service personnel, visitors must judge their own personal abilities in relation to each feature and offering of an individual park.

Copies of ***Access America: An Atlas and Guide to the National Parks for Visitors with Disabilities*** *may be purchased through the Exceptional Parent Library at $89.95 per copy, plus postage and handling,* *see page 75.*

NORTHERN CARTOGRAPHIC

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"A beautiful atlas." Stuart Mace, Program Services, National Easter Seal Society.

"Nothing less than a masterpiece . . . highly recommended." Library Outreach Reporter.

"Where can I find enough superlatives for this stupendous achievement?" Justin Wright, The Itinerary Magazine.

"Beautifully produced . . . a staggering amount of information relevant to the whole spectrum of disabilities." United Retirement Bulletin.

"I frequently receive information on accessibility. I have never seen anything as wonderful as this guide." Susan Kniestedt, Ex. Dir., Special Recreation Council of Greater St. Louis.

"Splendid piece of work." U.S. Senator Robert T. Stafford, Senate Subcommittee on the Handicapped.

"It is truly a groundbreaking publication." Robert Montague, Ex. Dir., Special Olympics.

The phrase "Access America" is the trademark of the U.S. Architectural and Transportation Barriers Compliance Board. Northern Cartographic disclaims any relationship with this federal agency.

Request your local library to acquire ***Access America*** ...

"Access America", 464-page atlas and guide text, special binding, full color, 250 maps. List price $89.95. 25% discount on personal copies or non-profit orders = $72.45 postpaid. Brochure available. Send to: Northern Cartographic, Dept. B, P.O. Box 133, Burlington, VT 05402. Or, call 802-655-4321.

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"I'm not still at home full time."

Problems in Summer Planning

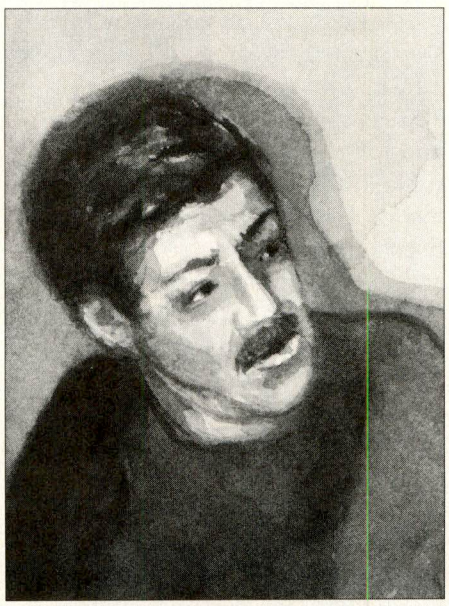
Charles Crowley, a short energetic-looking man, in his mid-30s, spoke quickly. "We are having a problem with planning our son John's summer. It came to a head last week when our older son, Paul, who is 13, asked to go to overnight camp. Paul has several friends who have been going to the same camp for some years, and January is the time to do something if we want him to go this year.

"After he left the room, my wife Judy wanted to know what we were going to do for our eight-year-old son, John. He has difficulty walking because of a minor disability and he also has problem in learning at school. We have never had an easy time planning for his summer vacations.

"Two years ago, we sent John to a YMCA program and it was a total disaster. We took turns taking him to the camp in the morning because he wouldn't go on the bus. Every day he used to cry before going. He was exhausted and upset at the end of each day; and the people at the camp didn't seem to know what to do with him.

"For some years the Y had talked about including kids with disabilities in their program; that summer was the first time they tried it. Although the staff seemed to be very enthusiastic before the program began, they didn't seem to follow through when things got tough. It seemed to me and Judy that when they had trouble they didn't do anything and certainly did not tell us about the problems.

"Last year John asked to stay home like the other kids in the neighborhood. We live right across from a nice playground with a large play area and some activities, although not particularly well



"I feel that we have too high expectations of our kids."

supervised. Lots of kids are around in our neighborhood and they usually do something with the counselors at the playground and then come home for lunch and play with each other. Because of the summer problems of the previous year, we gave Paul, who was 12, and Betsy, who was 11, some extra money if they would either play with or try to include John in their activities. They probably each spent an hour and a half a day at it. We also hired a tutor to come three afternoons a week for an hour.

"All in all, things seemed to be much more relaxed for John. The year before he was in no mood to go back to school; it took him a month to really settle down. Last summer he talked to a lot of the kids in the neighborhood and played with some of them. He seemed to be better off when he entered school, probably because he had made some friends.

"I've also felt that we have such high expectations of our kids. We expect them to work year-round and never to have any fun or relaxation. When I was growing up, my mother and father always had me into something. In the summer, I went to day camps or overnight camps. I always wished I could just stay home and relax. You work so hard in school during the year that it seems unfair to be expected to work in the summer also.

"This is a special problem with John because we don't want him to fall further behind. He does do things a little slower, but it seems to me, though, that he should have some chance to relax instead of dealing with all kinds of new problems in the summer.

"Judy enjoyed going to summer camp. She liked not being supervised by her parents all the time. Judy will tell you that she would like John to try another program this year. She felt he accomplished very little last summer."

"Summers and vacations are the only areas in which Charlie and I have any disagreements. I'm not still at home full time like he seems to think." Judith Crowley, a short, slender, youthful-looking woman, spoke softly. "We agree on everything else, what the kids should do, what the goals should be, how we should share household arrangements. We always have agreed. What we have differed on is what to do with our own vacations. This has become more complicated because of the kids, particularly now that the focus is on John. But I wouldn't want to forget Paul or Betsy either.

"I think Paul wants to go to overnight camp so he won't have the responsibility of taking care of John. Last year he was an important part of John's summer program.

"I am a schoolteacher, so I don't work in the summers. Let me tell you, I am the one who has the increased responsibility during the summer if all the kids are home. And particularly last summer, it made it look to Charlie like Paul and Betsy did the work and Sam Turner, who came to do the tutoring, did the teaching. But I still had to be available all day, because things didn't always work out. Some days Paul wanted to go off, or Betsy had a friend over, or John didn't want to go out. And I tell you, by the end of the summer I was so tired I wasn't at all ready to return to school.

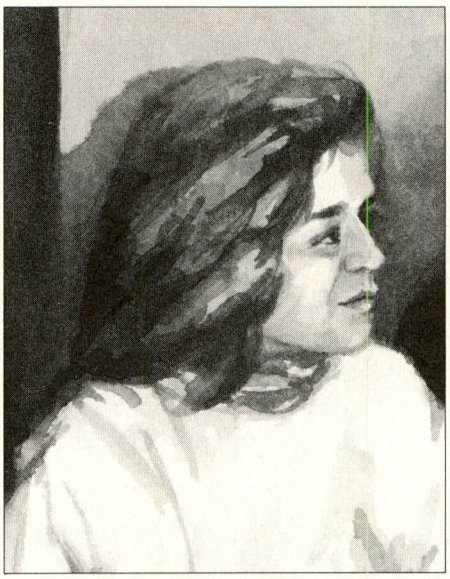
"For Charlie, winter vacations, when he is home with the kids, are

Illustration by Natalia Raphael

alright; they fit his work schedule. Those are times that we obviously can get somebody, my sister or Charlie's brother and his wife, who'll take the kids for a week. But I have to have some rest before the new school year starts. It may sound selfish, but it seems to me that we also have to think of the other kids, as well as ourselves.

"I also think that sooner or later, John has to do things outside of the family. We are a close family. I think the kids are terrific and very helpful all the time. But they're growing up and pretty soon they're going to leave home. In another few years, John is going to have to go to the junior high, which is combined with the high school on the other side of town. Sooner or later he is going to have to learn to accommodate people he doesn't know and kids he doesn't get along with.

"I also wonder how much schoolwork he should do in the summer. I know from the kids I teach that extra work in the summer doesn't help that much. What I expected from the tutor was help in knowing John's problems, so we could help his teachers more in the fall. That's partly why, when we discussed how to settle this, we thought of you because you know about education, as well as about summer planning."



"It may sound selfish, but we have to think of ourselves."

The Crowleys came because of a disagreement over summer plans for their son John. Judith Crowley agreed that the last summer arrangement had been helpful but demanded too much of her time and attention as well as that of their other children. She felt that John was ready to profit from a more organized community based program. She also agreed that they would have to find a better program than the one from the previous summer that had been a failure.

Charles Crowley thought his son should be allowed to stay at home as he had the previous summer. He believed that the school year was such a challenge that a more peaceful summer would be appropriate for him.

The role of summer programs is debated by families. Parents have their own history and experience with summer programs that shape their attitudes and behavior toward their own children.

Mr. Crowley had felt that when he was growing up, he was not listened to and was sent to summer camp against his own best wishes. Mrs. Crowley believed that going to camp had broadened her view of herself, expanded her skills and exposed her to youngsters she would have never known.

When a youngster in a family needs special help, it influences the decisions parents make about how to utilize family resources, both emotional and financial. The Crowleys had invested a great deal of time and energy in helping John. They had not spent as much time considering their own personal needs and wishes or those of their other two children.

Their older son's request to go to an overnight camp was the first time the Crowleys had to consider

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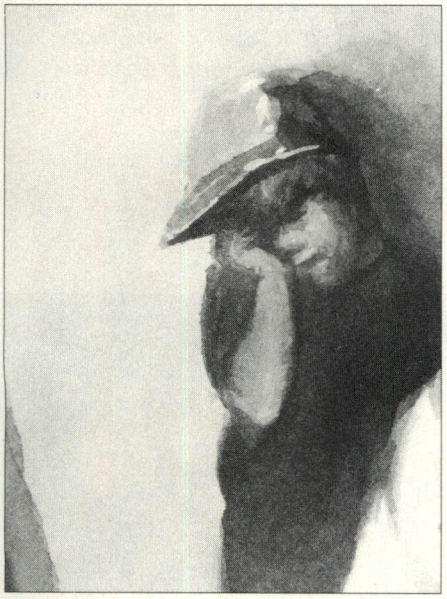
balancing the needs of all of their children. His request also forced the Crowleys to review the arrangements of the previous summer.

As families grow and develop, their needs, resources and decision making styles need to change. A style that might be appropriate when a couple first gets married may need to be considerably different when they become parents. As their children grow older, further changes may be necessary.

In the Crowley family, once their younger son John entered school, Mrs. Crowley returned to her profession as an educator. Prior to that, family vacations were organized around Mr. Crowley's



work schedule and the children's school schedules. This pattern continued even as the children grew older and Mrs. Crowley returned to work.

Nevertheless, family decisions were often made as if the Crowleys only had one child with a mother at home and a father at work. Mrs. Crowley found herself fatigued by the end of her school year, and she wanted to recoup her energies during the summer as well as take some courses that would enhance her own career. As a result, she had been interested in finding more structured programs for all three children.

Two years earlier, the Crowleys had tried a day-camp program for John that did not work out well. This made Mrs. Crowley more willing to focus on John's needs and abdicate her own during the previous summer. For the coming summer, she wanted to include the interests of herself as well as her older son and daughter.

Sometimes when a family has a child who has special needs, parents focus their interest and time on that child and do not make the necessary adjustments and considerations for other members of the family. As a result, the parents may end up not listening to anyone's needs, including their own. It was important for the Crowleys to include their children in a family discussion about the summer. This would enable them to know what each child thought would be important. Even when a parent cannot do everything a child wants, it is important to actively demonstrate interest.

The Crowleys arranged for a meeting the following week. They were surprised at how eager everyone was to discuss summer plans with each other. Initially, each child presented his or her own summer plans in terms of what he or she thought their parents wanted and expected.

John knew that he had presented problems for his parents not only during the school year, but also during the summer. He thought that staying at home would present the least demands on his family.

Paul, the older son, was concerned about the family's finances. The previous summers he wanted to stay around the house because he thought this was the least costly. He raised the question of overnight camp for this year because he had assumed that the family's finances had improved, and because he felt he had been putting off something he had wanted to do for a long time.

Mr. and Mrs. Crowley also discovered that Betsy had really

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wanted time to be with her mother, and had been spending the summers at home in order to be close to her. It was also clear that Betsy was better able to structure her activities around the playground than either of her brothers.

Mrs. Crowley was able to discuss her wish to have some time during the summer in which they all were together as well as to have some time during the summer for her own activities. Mr. Crowley realized how, while he was busy taking care of the family in his own way, he had assumed everybody was doing what they wanted to do. At the meeting, he also raised the problem of finding an appropriate program for John.

In recent years, community-based summer programs have expanded to include a whole range of children who had not been served before. When this first began to occur, both parents and program directors often lacked a clear understanding of the challenges and expectations.

Parents often have difficulty planning for a child with a disability. New programs may remind them of the inadequacies of their previous activities with the youngster. Parents are often puzzled about finding or evaluating a camp program for a child who has special needs.

Parents do know their children's limitations and what helps them adapt to living and playing at home, in the community and at school. This information can now be supplemented by their meetings with school personnel in planning their child's school program. They may also have a chance during the spring to meet with their youngster's teacher to get suggestions for the summer recess. This knowledge becomes the basis for evaluating any summer program.

John had friends who were going to the YMCA day camp. He had heard how much they had enjoyed the previous summer, and he wanted an opportunity to try again. Mr. and Mrs. Crowley went with John to meet the camp director and discuss the activities that they could expect and the kinds of adaptations that would help John be included. The family agreed to meet once more in the middle of June to have a last chance to discuss their summer plans.

-M.J.S.-

This case has been selected from private practice and consultation files. The names and circumstances have been changed to preserve confidentiality.

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LETTERS TO THE EDITORS

Continued from page 6

PROSPERING IN THE MAINSTREAM

When I read the article about Jason Elias mainstreaming (Prospering in the Mainstream, September 1988) in the Rincon Valley School District in Santa Rosa, California, I recalled how well my own son, Kevin Harrington, was treated when he attended Madrone School, Rincon Valley District, 1975-76 school year.

Kevin has muscular dystrophy. At that time, third grade, Kevin attended school half days because he was just about ready for a wheelchair but could still walk (much difficulty). Kevin was mainstreamed into a regular class and the district assigned an aide for him. This was right at the beginning of Master Plan and many schools had just started to think about compliance. The district really wanted Kevin to be part of a regular class and peer group.

Apparently, they have kept up the good work. Recently, I substituted in Jason's classroom at Binkley School, one of the district's middle-grade schools, and it seemed that, indeed, Jason acted and was treated just like a regular student.

Marian Harrington
Santa Rosa, Calif.

THE PRESSURES OF EARLY INTERVENTION

The article entitled "The Pressures of Early Intervention" (September 1988) highlights the variability in program goals and gives the impression that choices in early intervention programs are readily available. Here in Massachusetts, over 1,000 are clamoring for services — not postponing the decision to enroll — because they have been on waiting lists for admission for substantial lengths of time. In most areas of the country, there are no other developmental services available for infants and toddlers and parents have no opportunity to select among programs offering different philosophies of treatment.

There are some commonalties of program design that are fundamental in Massachusetts and in other states and will be even more widespread when P.L. 99-457 is implemented. In particular, the family focus of early intervention programs in this state differs from the habilitative programs exclusive child focus described in the article. We encourage early referral because admission to a program does not mean a child automatically receives a particular prototype of services.

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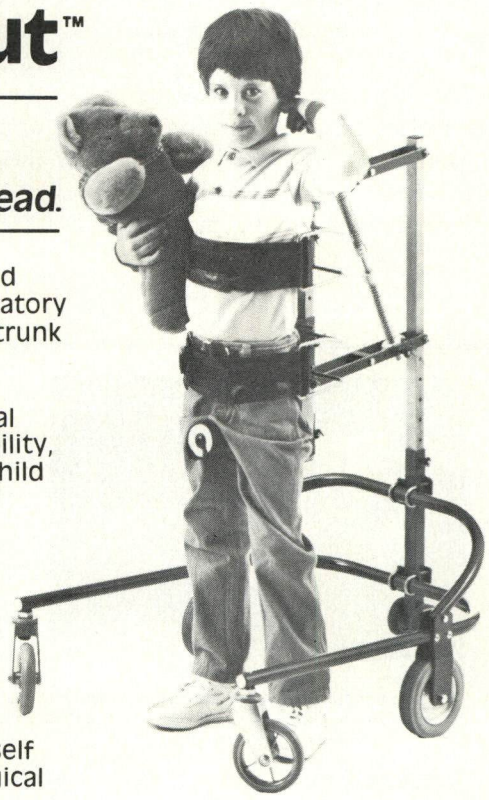

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Instead, parents are considered to be members of the team and decide when they want services to begin. They may avail themselves only of parent support and resource options while they help create a treatment plan that reflects their perspectives. The early intervention program is a logical place for families to network with others with similar concerns.

Our goal is not "to begin the process of remediation as soon as possible," but rather is to begin helping the family adjust to their particular situation as soon as they are ready. Programs are just as focused on addressing the support and informational needs of the family as on meeting the therapeutic and developmental needs of the child.

We applaud the increasing attention to early intervention afforded by EXCEPTIONAL PARENT and look forward to additional articles that provide balanced information about the state-of-the-art of this very dynamic, evolving field.

Tracy Osbahr, President
Mass. Early Intervention Consortium, Inc.
Northampton, Mass.

MORE KUDOS

The changes made last year in your format made EXCEPTIONAL PARENT much easier to read. The format makes the information easier to find and use, particularly when referring to back issues.

I have been a subscriber for several years, and the past two years, in particular, I have found the articles to have greater substantive value and the resource sections to be well-organized and informative. Keep up the quality!

Janis Boyd Hudson
Beaumont, Texas

EXCEPTIONAL PARENT IS SOLICITING YOUR QUESTIONS!!!

Although we continue to welcome letters from our readers on any subject, we would like to more systematically explore areas of day-to-day living. We are now soliciting questions in the following areas:

1). Toileting needs of your child.
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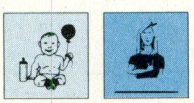
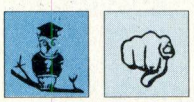


TO DEVELOP: Vocabulary and activities range from preschool to early academic level. A set of **new** icons targets children's individual needs and interests.



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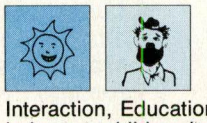

TO EXPRESS: Expressing feelings promotes social-emotional well-being. Icons depict a variety of emotions.

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A LETTER TO OUR SON

By Debbie Charette

Dear Anthony,

What better a time than your first birthday to let you know how very dear you are to us (Daddy, Mommy, and your brother, Joey). Unfortunately, the depth of the love we have for you could never be sufficiently expressed through words, but nonetheless I will try.

They say God works wonders, and you, our dear son, have been a true blessing in disguise. I must admit at birth a lot of emotions tried to take center stage, but the strongest emotion of all, that being our immense love for you, made all else seem less important to us. Don't get me wrong, there are those days when your future chokes us with frightened uncertainty, but your father and I have come to realize that if given the opportunity your brother Joey's future could cause us the same fears and anxieties. What we must focus our energies on is today, not tomorrow or yesterday! Sometimes the matters of today will have an effect on your tomorrows, so we can only pray that we gain strength and knowledge to make those tomorrows the best they could possibly be for you!

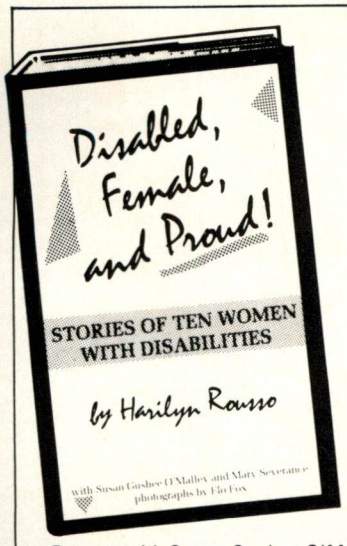
We have many hopes for you, dear son. Hopes that we, as a family, can help you obtain your fullest potential. Hopes that somehow we could return to you all the love you have given to us, and that you are so deserving of. Most importantly though, hopes that you give yourself the same unconditional love, and that you accept Anthony for the beautiful and special person he is.

I will end in saying Anthony, that in days to come if you ever find yourself in need of a great big hug from Daddy, Mommy, or your brother, Joey, and if for some reasons we are not in arms reach, you can always take out this letter and know that your family has always loved you for who you are—our Anthony!

Happy First Birthday, dear son!

All our love — all your life!

Practical and Up-To-Date Resource Books About Disabilities from Exceptional Parent Press.



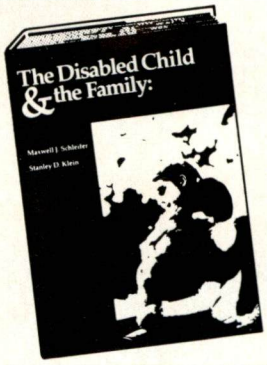
Exceptional Parent Press proudly announces the publication of **Disabled, Female, and Proud!**: *Stories of Ten Women With Disabilities* by Harilyn Rousso with Susan Gushee O'Malley and Mary Severance.

This book offers young women with disabilities empowering role models and the powerful message that they do not have to be or become any one thing because they are disabled and female--they have full lives ahead of them. It offers parents and educators a unique way to help young people learn that making choices--about school, work, family, and love--is what being disabled, female, and proud is all about.

"You do not have to be or become any one thing because you are a woman or because you have a disability. There are a range of possibilities from which you can choose." *-Harilyn Rousso*

"Don't overstate your disability and don't ignore it. Be assertive. Figure out what you want and don't let people who say you can't get there convince you that you can't do it. Keep fighting, keep using your head, keep finding as many avenues toward where you want to go as you can." *-Adrienne Asch*

"Value yourself, and realize your worth, and realize you're a person too. You have a lot to offer, so offer it. Go for it!" *-Linda Young*



"The Disabled Child & The Family seems ideally suited to the needs of parents and professionals alike. It offers a balanced examination of legitimate concerns for both these groups and poignantly emphasizes understanding the child as a whole individual rather than as a symptom or a disability.

This book vividly illustrates that mutual respect for everyone's knowledge and experience--parents' and professionals'--can open the way for children with disabilities to reach their full potential."

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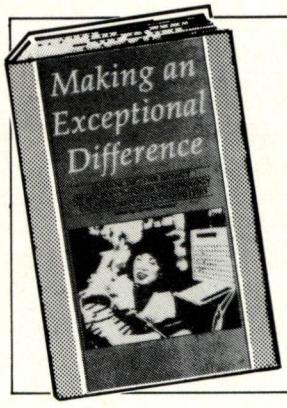
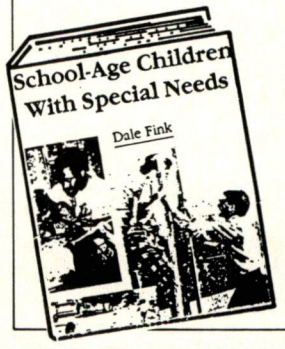


Making an Exceptional Difference is a compilation of articles that provides practical information about applications of technologies and approaches.

These articles were chosen because they:

1. are written clearly and require no previous technical knowledge to be understood.
2. describe ways in which computers can be used to make significant impact on people.
3. communicate the possibilities computer technology is opening up for people with disabilities without exaggerating the value of the computer as a miracle cure.



Are children with physical, mental, emotional, medical or other disabilities welcome to attend Extended Day Programs, Latchkey Programs, Kids Clubs, and other school age child care programs which have established across the U.S. in recent years? Or are they and their parents finding themselves shut out of these new initiatives?

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A VERY SPECIAL PERSON

by Emilie Lawrence

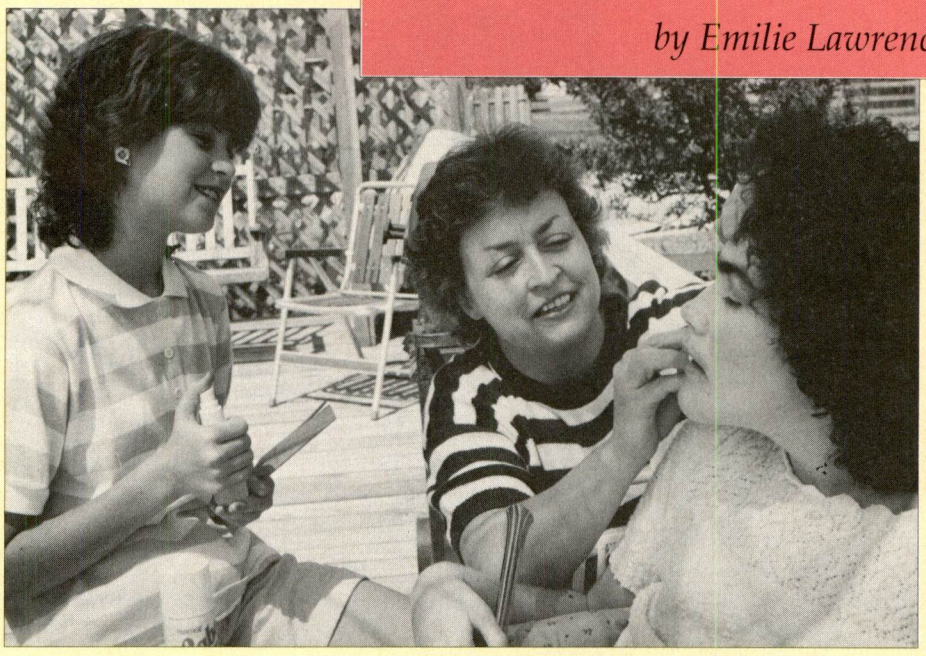


Photo by John Beckman © Quadrant 1988

Emilie, 11, and her mother, Susan, do Christi's hair. Emilie wrote this story for a school 4-H contest.

This is a story about my sister, Christi. I want you to know about a person who has had a lot of troubles in her life. In spite of these things, she has become the best person she can be.

Christi was born on March 24, 1971. She was perfectly normal. On April 21, 1971, four weeks after Christi was born, she was in a car accident. They took her right to the hospital. Even though she had a severe skull fracture, the doctors didn't think she had brain damage.

When Christi was six months old, the doctors decided she had brain damage and epileptic seizures. These two problems caused her to walk and talk more slowly than others.

When Christi was four she went to a special school called Msgr. Pitt. As Christi got older she went to another school called Churchill Park. When Christi was nine she was in the Special Olympics in swimming. She was in the Special Olympics for four years, she won seven medals and 14 ribbons. Christi has gone camping, hiking, and boating with her family. On vacation she has gone to Washington, D.C., Holiday World, and Disney World three times.

Another special time that Christi had was first communion. Christi didn't know enough about God when she was seven to make her communion, but she was able to make communion with me when I made it.

But as Christi got older, her seizures got worse. In about five years, she got stitches in her chin, her lip, her eyebrow, and her head. She also broke her leg once, her ankle twice, and her arm once. These injuries were all caused by seizures.

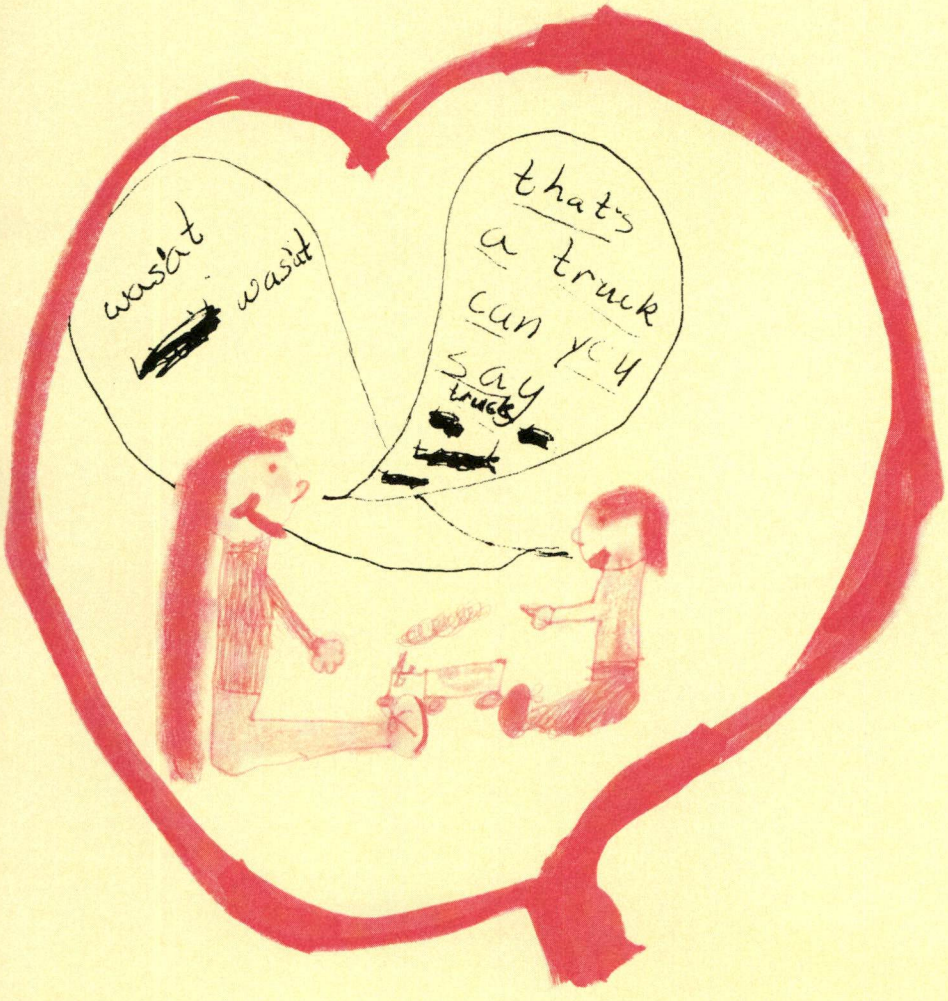
After our family thought about it we decided Christi should have a surgery that would help her seizures. She had the surgery on May 29, 1986. She was at the University of Minnesota hospital after the surgery for seven weeks. When she came home she had to be fed by a tube in her stomach, but since then she has learned to eat by mouth again. The surgery was not successful, and has left her paralyzed. But, as always, Christi has learned to make the best of her life.

And even though Christi can't walk or talk anymore, she can still do a lot of things, like when she is happy she smiles and kicks her legs. And when she is unhappy she cries and frowns to let us know how she feels. She goes to high school now. She likes to watch me compete in gymnastics. Last summer our family spent a lot of time together at the lake. Christi was able to go down the hill to go swimming and boating in a special trailer pulled by a tractor that our Grandfather fixed up for her.

I have told you everything about Christi and I just want to say I am very proud of my sister.

My Brother Benjamin

by Jennifer Carlson



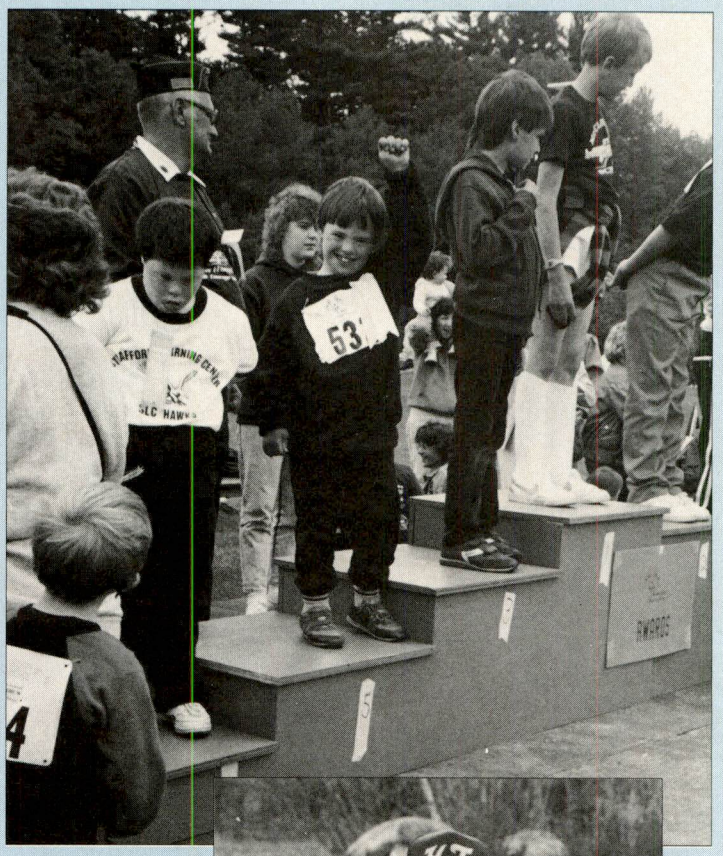
My brother is retarded, but that doesn't mean that we can't play and help each other. He's a great player, and I help him say words and stuff, like I am in this picture. Being retarded doesn't mean that people are gross or anything, it's just the way they are born.

Jennifer Carlson, nine, wrote this story about her brother Benjamin, four, who has Down syndrome. Also pictured is their baby sister, Kisa. The Carlsons live in Spring Valley, Minn.

Special Olympics

by Tom Moritz

Mike celebrates his winning day at the Special Olympics.



June 4, 1988,

The day Mike Moritz went to the Special Olympics. The first event was the standing long jump. Mike jumped three times. He won fifth place in the long jump.

His next event was the softball throw. He threw the softball three times. Mike won fifth place in the softball throw.

His last event was the 50-meter dash. Mike was in the lead for most of the time. Then this kid started to gain on Mike. He and Mike had a tie for the gold medal. They ran out of gold medals. Mike got a ribbon, and they sent a gold medal in the mail.

Tom Moritz, 11, is in the fourth grade at Henniker Elementary in Henniker, N.H. He wrote this story about his brother's trip to the Special Olympics. Mike is 8 and has Down syndrome.

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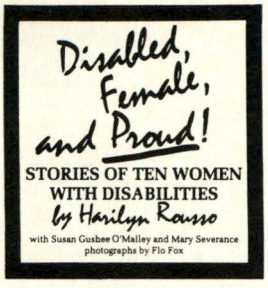

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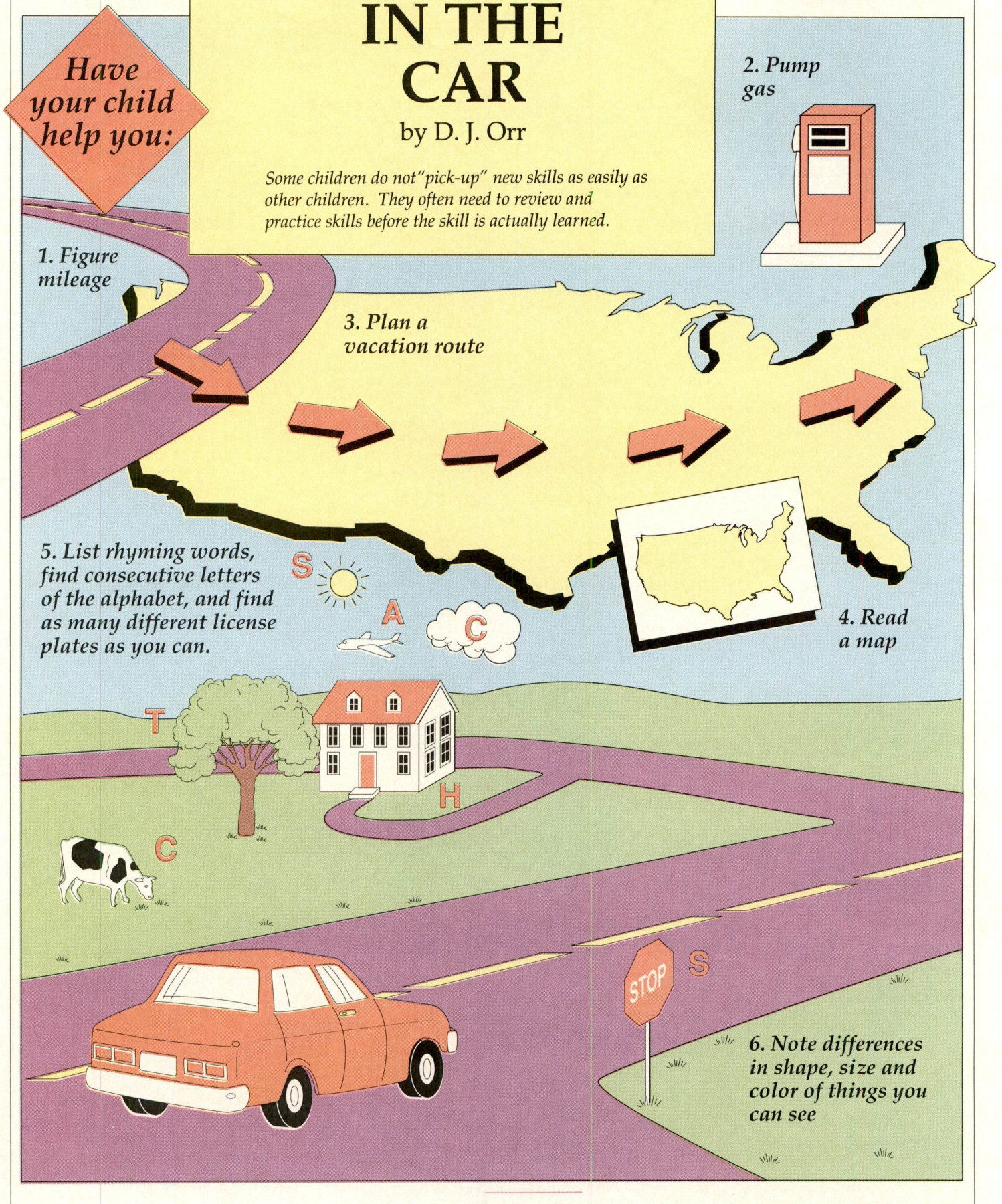
IN THE CAR

by D. J. Orr

Some children do not "pick-up" new skills as easily as other children. They often need to review and practice skills before the skill is actually learned.



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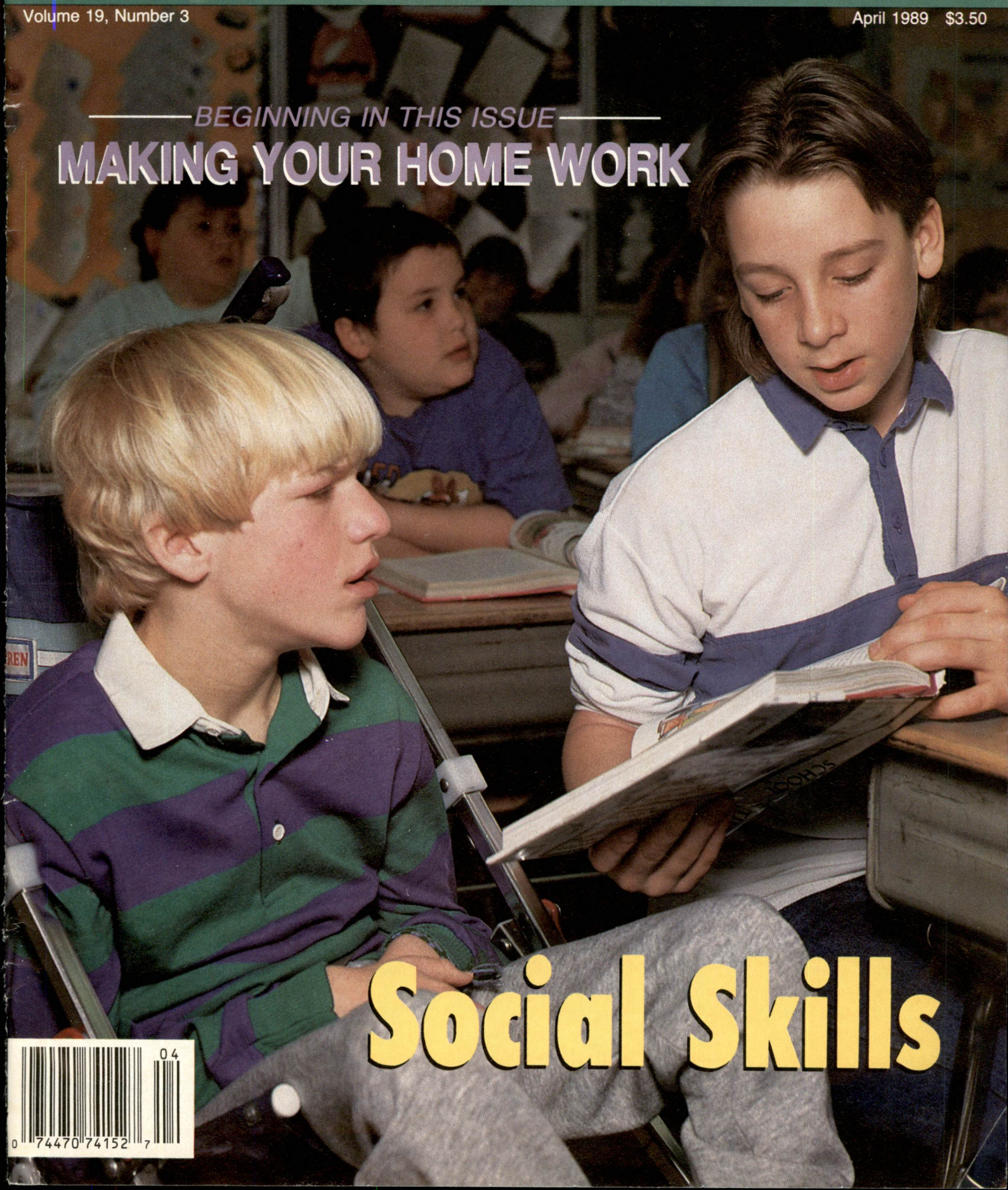

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EDITORS' DESK

Social experiences are valuable opportunities that enable us to learn about other people. They are the basics of developing and maintaining mutually satisfactory relationships throughout life.

This issue, we focus on ways to develop social skills for the entire family — *Putting the FUN Back* by Shari Weitzner is full of helpful suggestions on how parents of a child with a disability can socialize; *A Day with "B,"* our photo essay for this month, features Bjorn Kirkland, a boy mainstreamed in the Haverhill, Mass. public school system; *Social Integration: A Parental Challenge*, Brad and Stephanie Allen's article, describes how to develop your own techniques for managing your child in social situations; and *But Not Enough To Tell The Truth* by Helen Stavros and Richard Boyd, detailing how to serve the needs of the non-disabled sibling.

Finally, following last issue's theme of summer camp programs, Ann Shannon provides an useful alternative to camp in the article, *Peer Companion*.

MAKING YOUR HOME WORK: A NEW DEPARTMENT

Most readers are concerned about the day-to-day life of children who have, and are likely to continue to have, some difficulties getting around by themselves. For some youngsters, their disability impairs their capacity to walk unassisted. In addition, many youngsters have disabilities that interfere with eye-hand coordination or with the control of their arms and hands. As a result, they have difficulties eating, washing, dressing and participating in other everyday activities without the help of another person.

This month's installment, **Getting In & Out of Your Home**, describes how parents can utilize specific adaptive aids and other kinds of equipment to help children get around and enjoy life as much as possible while, at the same time, reducing a child's dependence on his or her parents' physical endurance. This issue will feature adaptive aids designed to improve access to the family home for the person with the disability. Future issues will move from room to room within the home, as well as include information on travelling.

Some parents may be able to construct adaptive equipment or install it on their own. This series of articles will identify the issues and illustrate commercially available solutions. Parents interested in exploring making products themselves can check with the clinical team and advocacy organizations for plans, suggestions, and, in some areas, specially trained architects and contractors.

MAY/JUNE ISSUE

We are pleased to report that we have heard from the White House that President George Bush will be responding to our Open Letter in the March issue in time for our May/June issue. Our May issue will also include the first report of the findings of the respite care survey that was distributed with our October issue.

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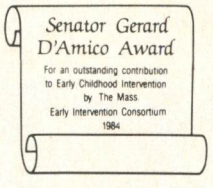

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EXCEPTIONAL PARENT®

Parenting your child with a disability

Social Skills

Volume 19, Number 3

APRIL 1989

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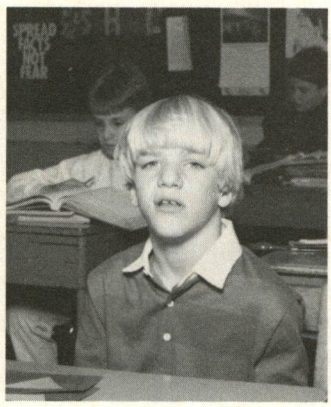

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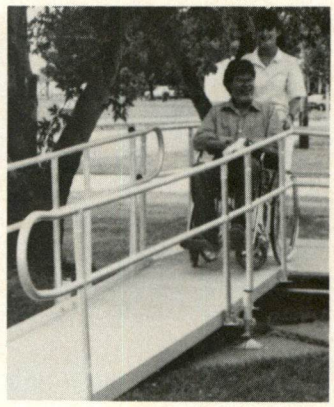

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Cover photo: Steve Fogg reads to Bjorn Kirkland in English class. Bjorn's story is featured on page 18. Photo by Cheryl Cullen.

LETTERS TO THE EDITORS

We welcome all contributions to Letters to the Editors. Please send your questions, ideas and responses to:

Letters to the Editors,
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MAINSTREAMING

The letter from Ronee Groff (January/February 1989, *Letters to the Editors*) serves as a reminder of the distance we still have to go to achieve full integration of children with disabilities in our public schools. We tend to congratulate ourselves on the accomplishments of special education since the implementation of P.L. 94-142 in 1975, but Groff jolts us back to reality. Clearly Groff believes her child is not reaping the benefits of those accomplishments.

As the author suggests, our colleges and universities do need to take a more responsible position in training teachers to enable students to succeed both academically and socially in mainstream education. We in teacher preparation programs tend to overlook or simplify the very real problems that exist in the schools' mainstreaming efforts.

However, even though problems continue, and teachers are not prepared as well as they should be, there is no evidence that we should abandon the goal of integration. We know for sure that all children learn academically and socially in mainstreamed settings, and that mainstreaming, when done well, is preferable to segregated education for many different reasons.

We need to keep in mind what we are striving for: individual achievements for our own children and full social integration of all persons with disabilities.

Mainstreaming remains a goal that propels our educational systems and teacher preparation programs, however inadequate they may be. Our jobs as professionals and parents is to continue to improve our practices and to renew our vision to reach that goal.

Parnel Wickham-Searl
Coordinator, Special Education
Dowling College
Long Island, N.Y.

I agree with the letter by Ronee Groff regarding her concerns about mainstreaming. For many years, my interest has been with deaf children, both as a speech-language pathologist and as a counselor.

I have witnessed, in many cases, the tremendous isolation that deaf students experience when placed in mainstreamed settings. Educational isolation occurs when teachers are not adequately prepared for the placement of a deaf student or when ancillary personnel (speech-language pathologists, counselors, psychologists) know little about deaf culture or sign language.

My other, and perhaps greater concern, is the social isolation faced by these students. They cannot, in many cases, communicate easily with peers, cannot participate in after-school activities, cannot develop those relationships that are so important in the development of positive self-esteem. Even with an interpreter, relationships are difficult because of the adult "middle-man."

Deafness is unique, with its own language and culture. Deaf persons are proud to be deaf and are proud of their heritage. Deaf children will grow up to be deaf adults. They need a sense of their past and a vision of the future — through studies in deaf heritage and contact with deaf peers and deaf adult role models.

For years, center-based programs for the deaf have provided a vast range of educational and social opportunities to deaf students. To many deaf persons and to educators in the field of deafness, this is the least restrictive environment. Mainstreaming, on the other hand, limits deaf students to a narrow world of restricted communication and restricted interactions.

Ginny Duncan
Harrisburg, Pa.

I am a parent of a six-and-a-half-year-old child with Down syndrome. Matthew has a twin brother, Michael, and a younger brother, Mark. As a family, we have strived towards normalizing our lives to the maximum. Unfortunately, we reside in a community that believes in segregation instead of integration.

Matthew is currently enrolled in our own community school in a special education class. He rides to school on the bus with his brother and is allowed to mainstream during recess and lunch.

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SPINAL CORD TUMOR

Our son was born with an extensive lipoma (fatty tumor) in his spinal cord. Matt is now seven years old and had half of the tumor removed when he was nine months old.

It has affected much of his body, specifically the T-2 and T-3 area of nerve function. This includes his lack of shoulder mass, contractures of his elbows, weak wrists and fingers. We are contemplating tendon transfers for his useless thumbs.

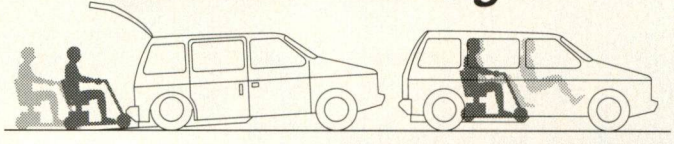
His balance is fair and he has to wear a foot brace to him from toe-walking on his right foot. He also wears a body jacket to hopefully prevent, or at least slow down, progressive kyphosis, a bending over of the spine.

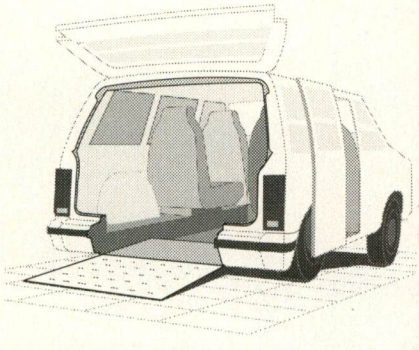
Matt has come a long way in dealing with his disability. He is a smart and sensitive child with a beautiful attitude and personality. We have learned a lot from him.

However, the struggle is on-going. We know of no one else having this condition and so have been on our own. We feel like trail-blazers and pray that we are doing the right things for Matt so that he can grow to be a "healthy" and fine adult. Please correspond with us if you have any information to share about spinal cord tumors!

C.W.
New York

Just glide inside, fasten your seat belt ••• and go.





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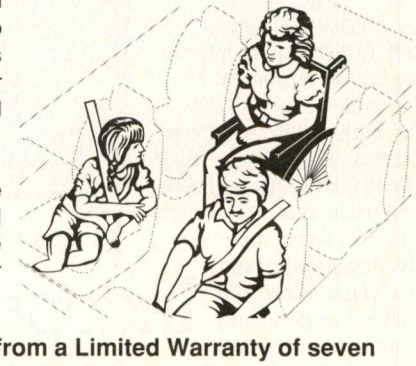

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USHER'S SYNDROME

Our five-and-a-half-year-old son has a profound hearing loss and very mild cerebral palsy. He uses sign language to communicate and does very well with it. We are very pleased with his progress.

Recently, he has been diagnosed as having Usher's syndrome — a form of Retinitis pigmentosa. We have been able to find very little information on this. We know it is a genetic disorder that causes hearing loss and degeneration of the retina, which eventually leads to tunnel vision. It is also quite rare.

We would love to hear from parents of children with Usher's syndrome or from anyone who would have information to share with us.

D.C. & C.C.
Alberta, Canada

Editors' Note: A reference book on Usher's syndrome, Usher's Syndrome: What it is, How to Cope and How to Help, *is available from Charles C. Thomas, Publisher, 2600 South First St., Springfield, Ill. 62794-9265, (217) 789-8980, for $24.75, plus $3 postage and handling.*

This book was sponsored and partially supported by the Center on Deafness, Western Maryland College, Westminster, Md. 21157. The center welcomes correspondence regarding Usher's syndrome.

Continuing . . .

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For more information, consult your dealer representative or contact the Chrysler Motors Physically-Challenged Resource Center at **1-800-255-9877.**

CHRYSLER MOTORS

NON-VERBAL CHILDREN

I am the mother of a six-year-old child with a developmental delay. She learned to walk at age five. She is almost completely non-verbal. She uses some signs, but because of poor fine motor skills, her signs are difficult to distinguish.

She is a bright, social child and is able to understand much more than she can communicate. I am interested in learning about any studies, research and/or programs involving non-verbal children.

T.V.
Washington

ARCHITECTURAL MODIFICATION

Our six year old son, Gavin, has spina bifida at the T-12 level, some fine motor skill deficits and upper trunk instability. He uses a wheelchair for most of his mobility, but we hope to see him walk someday. When he does, he will require much bracing.

Therefore, we are requesting information on architecturally modifying a home for him. Since Gavin's birth, we have moved about every 18 to 24 months, and he has always been small for his age. Stairs and flooring types have not been a major obstacle in our homes.

However, our next move will be permanent, which means that we need to place top priority on Gavin's future needs for mobility, safety, access and independence when purchasing a home for our family.

We probably will be relocating in the Denver, Colo., area, where most housing is multilevel with stairs and limited access to all areas of the home — both potentially dangerous conditions.

So we need information on building ramps, installing lifts, constructing sloping walkways and accessing the outside of a house, widening doorways, removing stairs, planning bathroom and kitchen modifications and selecting types of flooring material most suitable for wheelchairs.

We would like to hear from architects, contractors, landscape architects, manufacturers and suppliers, etc. Also, we'd like to correspond with other families to share experiences, ideas and suggestions with us since we are so uninformed on this subject.

We would like to see an issue of EP devoted to this subject.

Thank you for being such a wonderfully supportive magazine.

T.B.
Montana

Editors' Note: A new series on adapting your home begins this month, see page 26 for the first installment of Making Your Home Work.

KEEPING HEARING AIDS ON

Does anyone have a suggestion on how to keep hearing aids on a very active 16-month-old baby. Born three months premature, my son, Christopher, was not expected to live. His twin brother had no problems except low birth-weight.

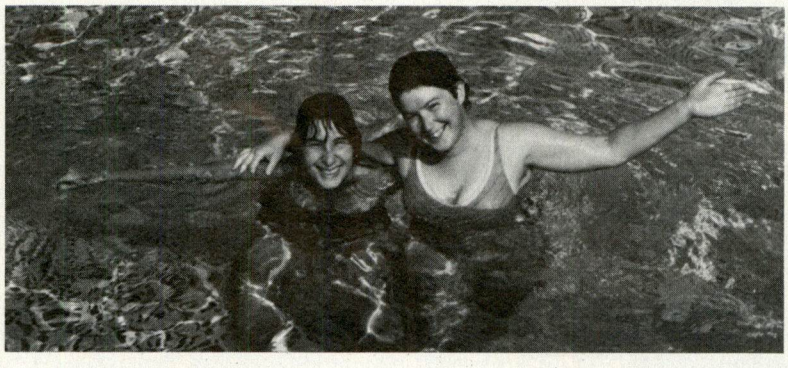
Christopher has broncho-pulmonary dysplasia and had a severe intraventricular hemorrhage. As he developed, the neurologist diag-nosed cerebral palsy, and I was told he would never walk without assistance.

Now, four months later, he is walking, climbing and even running if he's in a hurry. His hearing loss, however, is substantial, and he needs to wear the hearing aids at all times.

While his brother, Travis, is babbling and saying words, I have yet to have Christopher say "mama." I've tried everything to keep the aids on, but he pulls them right back out.

C.B.
Arizona

Day, Weekend & Weeklong Trips for People with Developmental Disabilities



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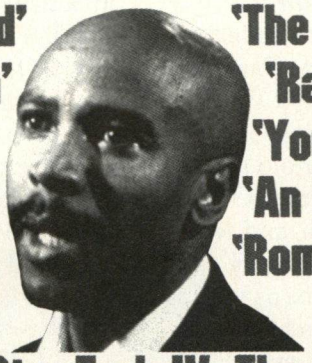
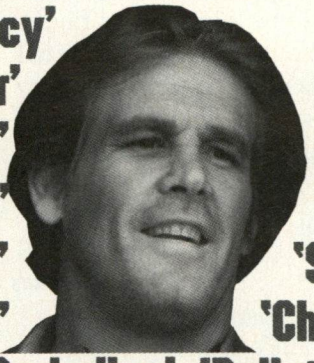
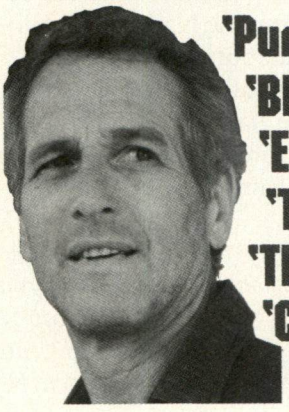
'Lasers: An Introduction' 'Raising Arizona'



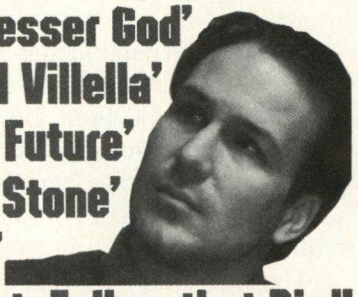
'Jagged Edge' • 'No Mercy' 'You and the Law'
'Encounter with Disaster' 'An American Tail'



'Time Changes the Land' 'Romeo and Juliet'
'Ferris Bueller's Day Off' 'Enemy Mine'
'Purple Rain' 'Star Trek IV: The Voyage Home'



'Blind Date' 'Children of a Lesser God'
'Extreme Prejudice' • 'Ballet with Edward Villella'



'The Color of Money' 'Back to the Future'

'The Miracle Worker' 'Gardens of Stone'
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'Harry and Son' 'Sesame Street: Follow that Bird'

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EXP/APR 89

PARENTS RESPOND

The following letters are in response to E.A.F.'s request for information on Goldenhar syndrome (Parents Search, November/December 1988).

We have a four year old son with hemifacial microsomia. Our Kevin has done very well, and will have ear reconstruction surgery beginning at about age six, as well as jaw surgery when he is in his teens. His hearing is very good, even though he has no hearing, other than conduction, in his affected ear.

We have been in touch with the the National Craniofacial Foundation, 3100 Carlisle St., Suite 215, Dallas, Texas 7520, since Kevin was two weeks old, and they have been a source of wonderful support and information.

They have a toll-free telephone number, 1-800-535-3643, and also put out a newsletter every few months. I think they could be a source of support for you, and perhaps head you in some appropriate directions.

I would be interested in finding out more about Matthew. Kevin has accepted his physical disability very well — he says his ear is "turned over" and that we will "get it fixed" when he is older.

S.R.
Texas

I read the article regarding hemifacial microsomia — Goldenhar syndrome in your recent issue of EXCEPTIONAL PARENT. There are numerous resources available to families of children with Goldenhar syndrome and other oral-facial and craniofacial disabilities. The national professional organization for physicians, therapists and others treating children with these problems is the American Cleft Palate/Craniofacial Foundation located at 1218 Grandview Avenue, Pittsburgh, Pa., 15211, (412) 481-1376.

The American Cleft Palate/Craniofacial Foundation has information available on hemifacial microsomia and also maintains a list for the National Cleft Palate Parents Association members.

Additional information dealing with hemifacial microsomia can be obtained from the National Craniofacial Foundation in Dallas, Texas. There is also information available through the National Organization for Rare Disorders (NORD), P.O. Box 8923, New Fairfield, Conn. 06812.

Marilyn A. Cohen
Regional Cleft Palate Program
Cooper Hospital/
University Medical Center
Camden, N.J.

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*Loading requires a Memory Transfer Interface

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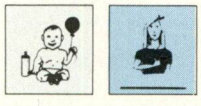
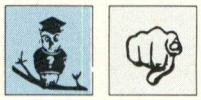
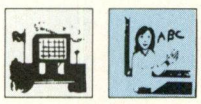


TO DEVELOP: Vocabulary and activities range from preschool to early academic level. A set of **new** icons targets children's individual needs and interests.



TO INITIATE: Interactive dialogues and a vocabulary of 100 different sentences, representing a range of pragmatic functions, facilitate the development of interaction skills.



TO LEARN: Vocabulary facilitates active participation in a variety of classroom activities.

TO PLAY: Stories, songs, and nursery rhymes teach children to communicate through play.

TO CREATE: A flexible vocabulary promotes freedom of expression. A core vocabulary of 500 words, including articles, pronouns, prepositions, and different verb tenses, enables nonspelling children to generate new messages.

TO EXPRESS: Expressing feelings promotes social-emotional well-being. Icons depict a variety of emotions.

Interaction, Education, and Play gives you time — time to help your child learn the program, to acquire new language skills, to be better communicators. Interaction, Education, and Play helps your child toward better communication.

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SOCIAL SKILLS:
Coming of Age

In his valedictory address on the occasion of his graduation from a suburban high school noted for its high academic standards, a young man with a severe hearing impairment expressed, via sign language, that his high school years had been lonely ones for himself, and for other students with disabilities, because they had been excluded from the after-school life of their classmates.

Today, as more and more youngsters with disabilities are being mainstreamed in educational settings, they are learning to make friends. Younger children are learning the basics of taking turns and sharing the attention of others, learning to use the telephone, and enjoying the giggly play and birthday parties of their young friends. Older children are learning to share and trade collectibles, to visit at a friend's home, to stay over with a friend and stay up too late, or just to hang around and talk or play. And teenagers are learning about the complexities of the adolescent social scene.

Some children with disabilities have an especially difficult time becoming involved in opportunities to learn social skills when other children mirror our society's overemphasis on appearance and physical, athletic skills.

Social experiences are valuable opportunities that enable all of us to learn about other people. They are the basics of developing and maintaining mutually satisfactory relationships with other people throughout life. Until recently, learning specific social skills has been left to the informal learning process of the playground, the neighborhood, and the family. Recently, we have begun to introduce the teaching and learning of social skills in classrooms, as we have understood how necessary they are for coping with the changing challenges of growing up from pre-school through high school.

Some children with disabilities have an especially difficult time becoming involved in opportunities to learn social skills when other children mirror our society's overemphasis on appearance and physical, athletic skills. In reference to appearance, a recent letter from a reader objected to advertisements in our magazine illustrated by children who are not disabled, as seen by the letter writer. The reader suggested that such illustrations demonstrated that society does not like the appearance of children with disabilities.

How does a child with a disability look? On our covers, we have tried to illustrate that children with disabilities can be happy participants in the joys of growing up. At the same time, we have acknowledged again and again in the pages of the magazine the importance of helping children learn to wash, to dress, and to "look" appropriate in order to facilitate social acceptability. At times, such efforts are criticized as trying to cover up and conform to the cultural expectations generated by Hollywood standards of attractiveness.

In our efforts to "discover" children and adults for our covers, we have been thrilled by the excitement of parents and children who want to be seen as they are. These parents and children love each other regardless of external appearances, intellectual skills, or athletic prowess -- these are powerful messages for all of us.

Positive interactions between children with disabilities and other children are the foundation of inclusion in a greater society. Many events have contributed to changing the expectations of children and adults in their interactions with children with disabilities. The greatest change has come from personal acquaintances.

As larger and larger numbers of children with disabilities have entered our schools and our communities, and as adults with disabilities have begun to play a more visible role in community life, people without disabilities have discovered that those people, young or old, with disabilities, are people with attitudes and skills and wishes and desires like everyone else.

In that sense we have all begun to change the attitudes of society. In that process, people with disabilities — children and adults — have become more attractive.

—M.J.S. & S.D.K.—

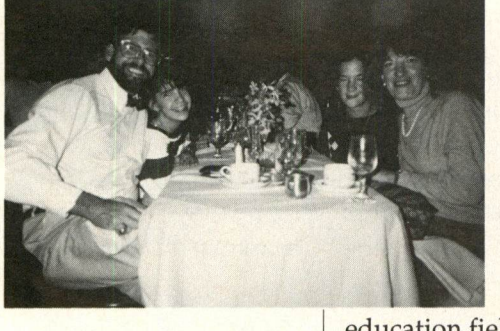
Putting the FUN Back

The Right To A "Normal" Life

A child does not take away your right for happiness and independence.

Recently, I was asked to give a speech to parents of very young children with disabilities on the topic "How to put the fun back in your life after having a child with a disability."

I was struck by the complexity of the subject. So many of my friends and neighbors are "stressed out" from jobs, family life and daily living without the day-to-day emotional roller coaster of living with a child with a chronic problem. How can we then handle this added burden in addition to all the other demands in our "push-push" lives?



by
Shari Weitzner

I looked the subject up in several sources and obtained some valuable information. I was able to document the reality of the serious, long-term effects of the burden we carry, such as the increased rates of divorce and depression in our families.

Although this information is important, mostly I want to speak from the heart, because, although I am a professional in the special education field, my real expertise and understanding (and I'm a snob about it) comes from being there, from having a child with a disability. I consider this to be a gift that my daughter has provided me with — it gives me an advantage when communicating with other parents.

Let me give you a little more information. I've been married for 19 years to the same man and have two children. My 16-year-old daughter, Sally, is mentally retarded. She was born with several medical problems including a heart defect. Her first year of life was rough with several hospitalizations and medical crises. Sally has a severe speech impediment, making her very hard to understand. My second daughter, Jill, is 14 and perfectly fine.

EVERYTHING CHANGED

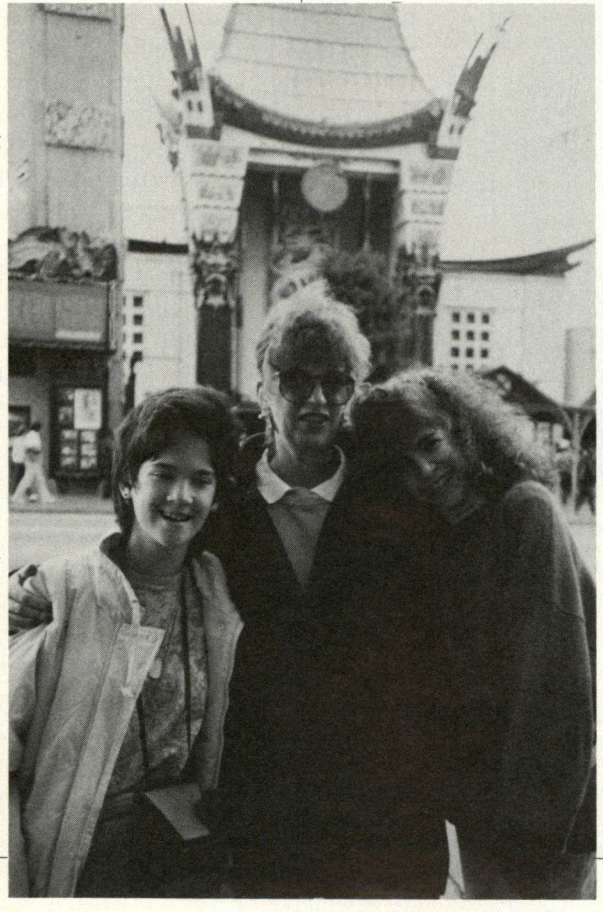
The first year of Sally's life is still vivid to me. It was a frantic time. I was depressed, anxious, stressed, uncommunicative, despondent, panicky and totally

Shari and her husband, Jeff, relax after a race.

absorbed in my new baby. Everything changed. My husband and I were no longer a young, healthy, carefree couple anticipating a normal family life. We began the process of grieving.

Basically, my entire personality changed. My husband's did too, but to a lesser extent since he went off to work every day. I stayed home dealing with the definite added demands of a child with a disability. My husband's upsets were certainly a reaction to my depression. The marriage became quite strained. Sally became the focus of my life; essentially, she controlled my life.

I'll never forget, as our marriage continued to be stressed, the comment of a marriage counselor we sought for help when Sally was three and Jill was one. After unburdening myself to him and explaining my unhappy emotional status, he blithely commented that my problems bore no relation to Sally. He said I was "copping out" in suggesting that she could produce any stress in my life!!!



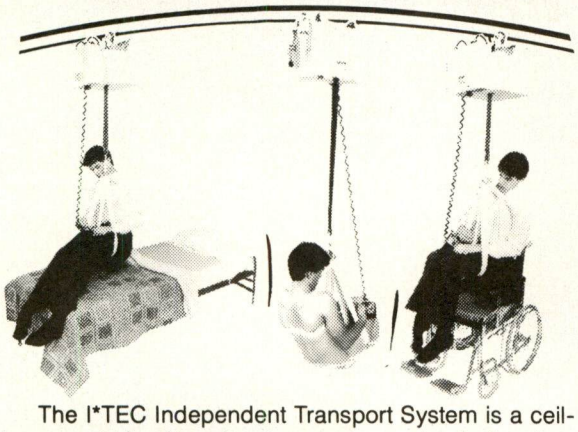
Through the years, my behavior with Sally has revolved around a couple of themes, at first on more of an unconscious level, but now more obvious to me.

I COULD MAKE HER NORMAL

First, I thought that if I worked hard enough with her I could make her normal. And when

Shari Weitzner with her two daughters, Sally (left) and Jill.

INDEPENDENCE



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Taking a break will affect you in a positive way.

one is focused in this one direction, it's pretty hard to relax and enjoy life. My frantic interventions with her were constant when she was younger and only with strong self-discipline have they decreased recently. After all, here I was a special education teacher. If I could teach other children, I could certainly teach Sally.

My behavior with her and my other daughter has been different. I would always engage Sally in some "important" educational game, something therapeutic. Neither she nor I were happy. I often worked with her to the point where I would be in tears, and she would be on the verge of a tantrum. I was so intense that my husband would have to order me to stop working with her.

SACRIFICING MYSELF

The other component of my behavior was the idea that if I sacrificed and worked hard enough with Sally, I could rid myself of the guilt I felt for in some way causing her problems. Psychiatrists would have a lot to say about this. Guilt is powerful. It's hard to enjoy life while you are wallowing in it.

Guilt is non-productive, as is blaming yourself, your husband, your doctor, the food you ate while pregnant, or anything or anyone else for your child's problem. While I was engaging in this obsessive-type behavior I had little time for other people, other interests or for myself. I believed that no one could help Sally as well as I could and that no one else knew how important these constant interventions were to her future.

TRUTH HURTS AND HEALS

This all brings me to the hardest part -- acceptance of the truth. It hurts, and we can all arrive at this acceptance only gradually over time. When we are able to come to grips with our children's problems, to face them squarely and rationally, then we can begin to find peace.

This is the key. You cannot do it all, change it all or fix it all. To help your special child, you must take

care of yourself as well as the needs or your husband or wife and other family members.

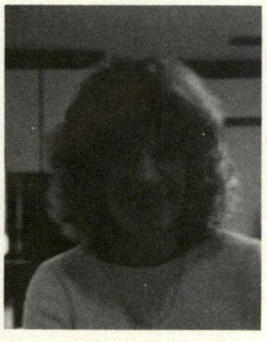
GETTING OUT BY YOURSELF

So begin by getting out by yourself or with your spouse. If this causes apprehension, start leaving for very short periods at first. Where should you go? Anywhere — movies, a walk, dinner — but go by yourselves and without guilt. Gradually try to let go of the notion that your existence revolves only around your child. The child does not take away your right for happiness and independence. Your state of relaxation after having a break from daily demands will affect those around you in a positive way.

For some, getting out and finding other outlets may involve joining support groups concerned with children with disabilities. This is often very therapeutic, but consider that a total immersion in the world of exceptionalities is not really a respite. Bowling, for example, is. As a matter of fact, physical exercise is wonderful. I have been jogging now for over 10 years, and my half-hour run really allows me time to sort matters out and put things into perspective.

Now that I have stressed the need for free time out, who will watch your child? This is an obstacle, but not an insurmountable one. Try other family members. If they don't offer, be assertive and honest and request their very needed and very appreciated help. Ask friends and neighbors. Rack your brain — you'll find someone. Also, the next time someone asks you how they can help, tell them. Don't be too nervous, proud or shy to accept such an offer.

Remember, this is an uphill battle. Children with disabilities potentially create disabled families. Force yourself, if necessary, to find new experiences. You won't regret it. Focus on your right to have a "normal" family life and to live a part of your life that does not include your child. Strive for a lifestyle that is diversified and allows independence, and you, as well as your loved ones, will benefit greatly.



Shari Klein Weitzner received her master's degree in special education from the University of Pittsburgh. She is currently an educational consultant at Hope Haven Children's Clinic in Jacksonville, Fla. Mrs. Weitzner lives with her husband Jeff and daughters, Sally, 16, and Jill, 14.

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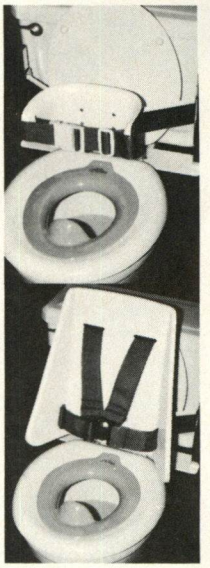

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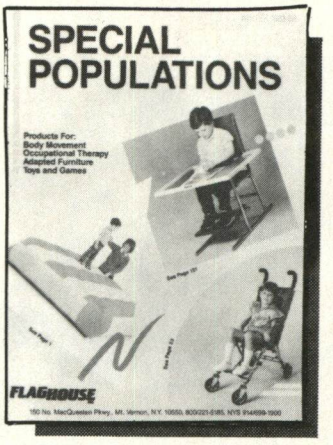

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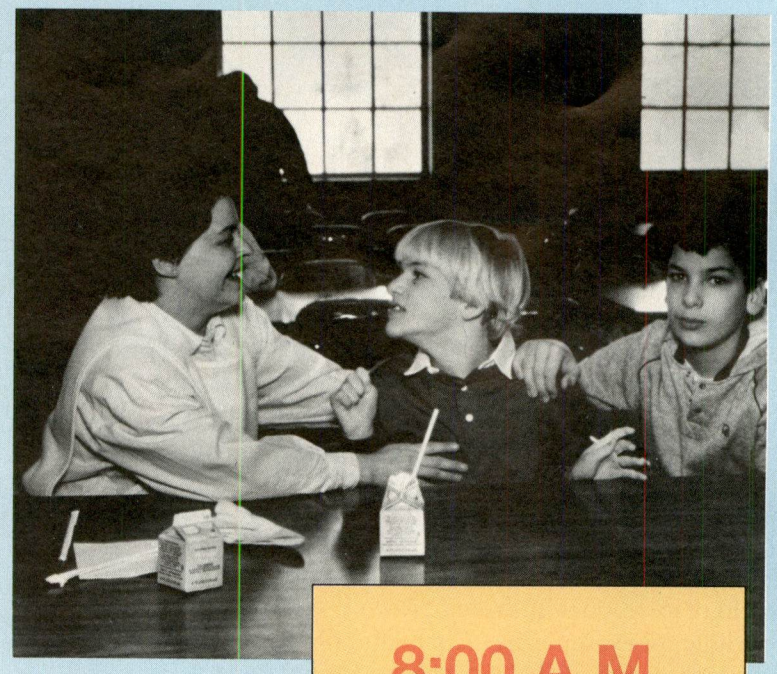
A DAY WITH "B"

Bjorn Kirkland is affectionately known to his classmates as "B" at the Consentino Elementary School in Haverhill, Massachusetts. Bjorn is 12 years old and has hypsarrhythmia, a brain wave disorder. We follow him on a typical day in the mainstream.

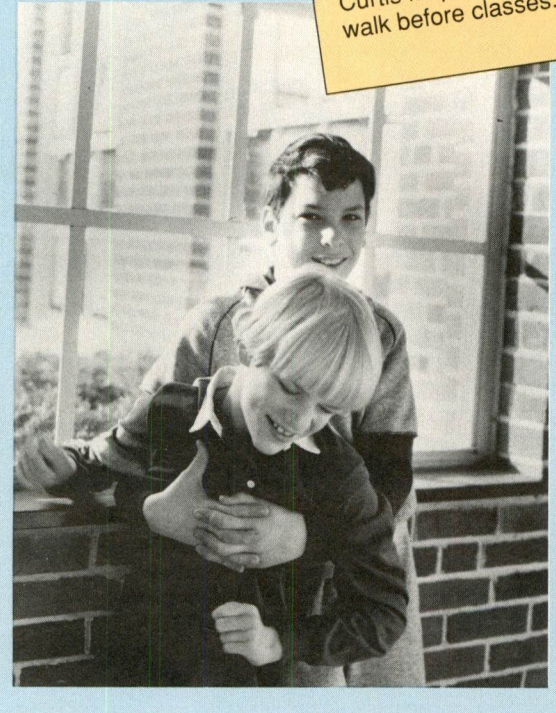


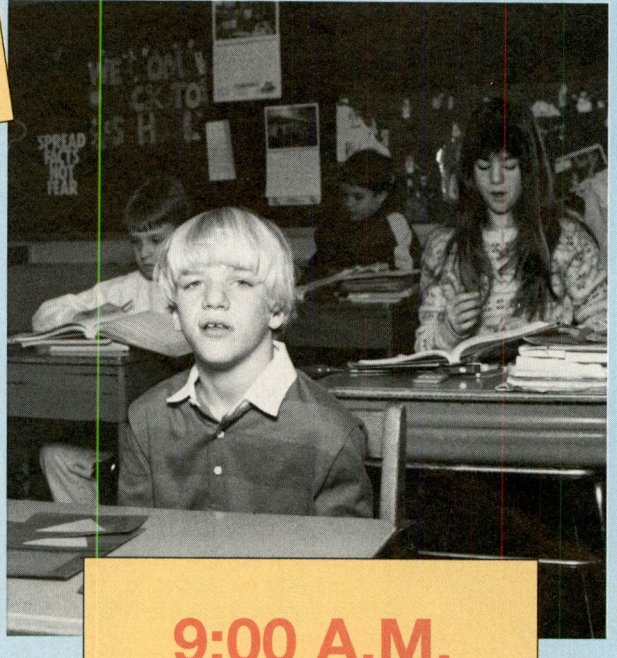
8:00 A.M.

In the morning, Bjorn meets Curtis Neavill, 11, and his aid, Dorette Sims, for an early breakfast.

8:15 A.M.

Curtis helps Bjorn on his morning walk before classes.





9:00 A.M.

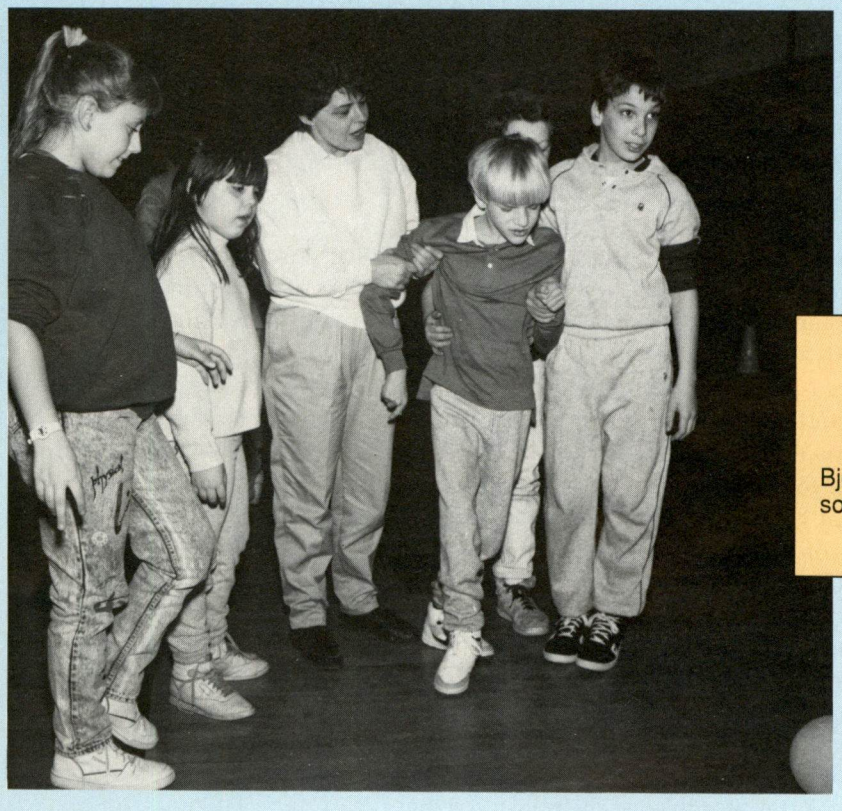
Bjorn in Mr. Mendelson's math class.

10:00 A.M.

In Mrs. Ryan's English class, Bjorn is read to by Chrystie Madore. Students regularly take turns reading to Bjorn.

12:00 NOON

Bjorn eats at the cafeteria with Curtis.



2:00 P.M.

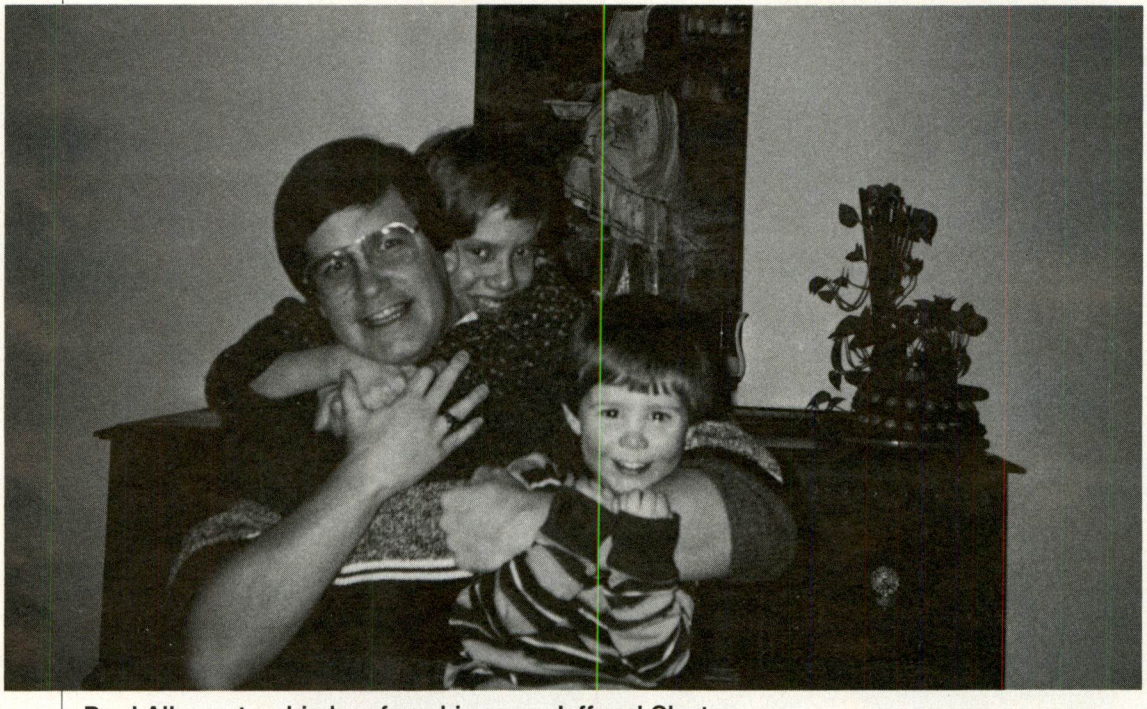
Bjorn plays ball in gym class with some of his friends.

Photos by Cheryl Cullen

SOCIAL INTEGRATION:

A PARENTAL CHALLENGE

Developing your own special techniques for managing your child.



Brad Allen gets a big hug from his sons, Jeff and Clayton.

by
Brad and
Stephanie
Allen

As the parents of children with developmental disabilities, we've all been there. The waiter has just left your table with an order for your favorite meal. The restaurant's atmosphere is very soothing, and you're looking forward to an enjoyable evening out with the family. Just as you feel yourself relax, out of the corner of your eye you see the blur of your son's or daughter's arm as it snatches up a fork and, with amazing accuracy, tosses it toward the group of very large people seated at the adjoining table.

Or, as your minister, priest or rabbi makes that dramatic pause in a special sermon, your son or daughter decides, for no apparent reason, to review his or her vocabulary of four letter words — at the top of their voice! Amidst the icy stares and loud whispers of condemnation, you can't help but wonder how South America is this time of year.

Needless to say, the experiences we've just described, or ones like them, can have a profound effect on how you plan future family activities. The feelings of embarrassment and frustration are beyond words. Yet we continue to involve our son, Jeff, in as many social events as possible despite ours and other people's misgivings.

Still, every now and then, especially after going through several difficult experiences in a relatively short period of time, we find it necessary to re-evaluate Jeff's needs and how we can best provide for them.

NORMALIZATION

Before becoming parents, we were (and continue to be) professionals in the field of developmental disabilities. After spending years working with many socially isolated and lonely people, we felt compelled to adopt the "Principle of Normalization," which is based on the idea that people with disabilities have a right to live as "normal" a life as possible.

Consequently, with a sense of moral obligation, we set out to include Jeff in the events and activities that are typical of other children his age. As we soon realized, our efforts resulted in our becoming behavioral specialists of sorts.

"We set out to include Jeff in activities that are typical of other children his age."

PLANNING AHEAD

We have often found the most effective technique to be a combination of disarming our son's disruptive behavior quickly, while anticipating situations that might lead to these behaviors.

Perhaps our greatest area of proficiency is our ability to evaluate his mood and plan appropriate activities accordingly. For example, if Jeff is in a "bad" mood, he is capable of many disruptive and socially inappropriate behaviors such as swearing loudly, throwing objects, engaging in self-abusive behavior, and striking out at people around him. When he is in this state, we try to choose family activities where we can control the physical environment as much as possible.

Bright lights, loud noises, extreme temperature and large crowds usually exacerbate Jeff's negative mood. It is also important that we avoid activities that restrict Jeff's movements since he can become very agitated if he can't move around freely when he's unhappy.

Although we try to ensure that he can move freely about, at the same time we try to limit his accessibility to objects and/or people if he's displaying aggressive behaviors. The best strategy at these times is to try to limit or eliminate his opportunities to act out in a socially inappropriate manner.

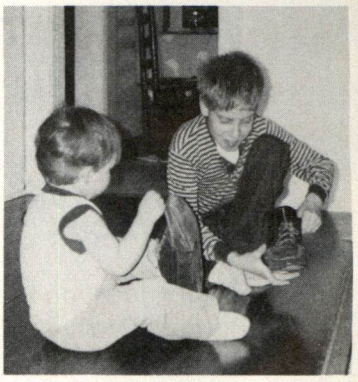
Many times effective time management is the key element in managing Jeff's behavior. Consequently, it is extremely important that activities flow smoothly so that there aren't any long delays.

Finally, we always try to reward Jeff when he exhibits appropriate behaviors with praise, hugs, etc. so that he will eventually learn the behaviors that are expected from him in certain social situations.

LONG TERM COMMITMENT

As the parents of a young man with a developmental disability, we've been faced many times with the dilemma of whether or not we should take our son to social activities because of his disruptive behaviors. As we've learned over the years, our approach to this problem is a life-long commitment to certain goals for our son, not a single, simple decision. That is, we have committed ourselves to include our son in as many social activities as possible because we feel that these experiences will enrich his life.

However, we also feel that we must not impose our ideals on other people to the point that we interfere with their freedoms. By developing our own special techniques to assist our son with managing his behaviors, we are able to support his participation in many social activities and, at the same time, not interfere unduly with the activities of the people around us. This is the true challenge for parents who want to socially integrate their child with special needs.



Jeff and his brother, Clayton, try on Dad's shoes.

Stephanie Allen (pictured right) is the Services Director for Advocates for Retarded Citizens (ARC) and is currently working on a B.A. in management. Brad Allen has a Ph. D. in educational psychology from Marquette University and is fulfilling the requirements for licensure in psychology. The Allens live in Shorewood, Wis., with their two sons, Jeffrey, 14, and Clayton, 2.

Augmentative/Alternative Communication Directory

ASSOCIATIONS AND ORGANIZATIONS

Special Education Software Center
Building B, Room S312
333 Ravenswood Ave.
Menlo Park, Calif. 94025
For technical assistance, call 1-800-223-2711; TTY: 1-800-435-7639
For software information, call 1-800-327-5892

The Boston Computer Society —
SNUG (Special Needs Users Group)
One Center Plaza
Boston, Mass. 02108
(617) 367-8080

International Society for Augmentative and Alternative Communication (ISAAC)
P.O. Box 1762, Station R
Toronto, Ontario, M4G 4A3, Canada

Computers Users in Speech and Hearing (CUSH)
School of Hearing & Speech Science
Ohio University
Athens, Ohio 45701

American Voice I/O Society (Voice Input/Output Society)
P.O. Box 60940
Palo Alto, Calif. 94306

The Council for Exceptional Children (CEC)
•Center for Special Education Technology Information Exchange
1920 Association Drive
Reston, Va. 22091
•Technology and Media Division
9366 Mellenbrook Road
Columbia, Md. 21045

Northeast Communication
Enhancement Group (NCEG)
P.O. Box 241
Winchester, Mass. 01890

Pacific Northwest Non-Vocal Communication Group
Membership Committee
Dept. of Rehabilitation Medicine
PJ-30
University of Washington
Seattle, Wash. 98185

COPH-2
(The Committee on Personal Computers and the Handicapped)
2030 W. Irving Park Road
Chicago, Ill. 60618
Link & Go Newsletter

Association for the Advancement of Rehabilitation Technology
(Previously RESNA)
1101 Connecticut Ave., NW,
Suite 700
Washington, D.C. 20036

Augmentative Communication Enterprises, Inc. (ACE)
551 East Columbus Ave., Suite 102
Springfield, Mass. 01105
(413) 737-7368

SOFTWARE: DIRECTORIES, DEVELOPERS AND VENDORS

Public Domain Sources for Education Software:

Software Shopper
Compiled by: Sandra Hart-Davis
Developed by: Outreach, Pre-College Programs, Gallaudet University, Washington, D.C.
Available from: D & H Associates
1391 Meadowbrook, N.E.
Palm Bay, Fla. 32905
(305) 725-5558

Public Domain Software
Colorado Easter Seal Society, Inc.
Computer Resource Center
5755 W. Alameda
Lakewood, Colo. 80226
(303) 233-1666

Resource Directories:

Closing the Gap
(Feb/March Resource Directory)
P.O. Box 68
Wenderson, Minn. 56044
(612) 248-3294

Rehabilitation/Education Resource Book 3 - Computer Software & Hardware, by Sara Brandenburg & Greg Vanderheiden
Trace Research & Development Ctr.
S-151 Waisman Center
1500 Highland Avenue
Madison, Wis. 53705

IBM Software for Education, (August 1986)
IBM Corporation, Dept. 8WH,
P.O. Box 2150, Atlanta, Ga. 30035.

Education Software Directory, (1985)
Electronic Communications, Inc.,
1311 Executive Center Dr., Suite 220
Tallahassee, Fla. 32230

Software Directory for Communication Sciences and Disorders American Speech —
Language Hearing Foundation
10801 Rockville Pike
Rockville, Md. 20852
Attn: Publication Sales

Software Developers/Vendors:

Peggy Barker, Rehabilitation Engineer
Children's Hospital at Stanford
520 Sand Hill Road
Palo Alto, Calif. 94304

Institute on Applied Rehabilitation Technology
Children's Hospital
300 Longwood Avenue
Boston, Mass. 02115
(617) 735-6466

Don Johnston Developmental Equipment
981 Winnetka Terrace
Lake Zurich, Ill. 60047
(312) 438-3476

Exceptional Children's Software
P.O. Box 4758
Overland Park, Kan. 66204

Laureate Learning Systems
110 East Spring St.
Winooski, Vt. 05404
(802) 655-4755

College-Hill Press
4284 41st St.
San Diego, Calif. 92105
1-800-854-2541

Parrot Software
P.O. Box 1139
State College, Pa. 16804
(814) 237-7282

Peal Software
5000 N. Pkwy Calabasas, Suite 105
Calabasas, Calif. 91302
(818) 883-7849

R. J. Cooper & Assoc.
2144 S. 1100 East, Suite 150
Salt Lake City, Utah 84106
(801) 263-1388

Schneier Communication Unit
Cerebral Palsy Center
1603 Court Street
Syracuse, N.Y. 13208
(315) 455-7591

Sunburst Communications
39 Washington Avenue
Pleasantville, N.Y. 10570
(914) 769-5030 or
1-800-431-1934

Sunset Software
11750 Sunset Blvd., Suite 414
Los Angeles, Calif. 90049
(213) 476-0245

Trace Center
S-151 Waisman Center
1500 Highland Avenue
Madison, Wis. 53705
(608) 262-6966

Washington Research Foundation
U District Bldg., Suite 322
1107 NE 45th St.
Seattle, Wash. 98105

Davidson & Associates
6060 Groveoak Place, 112
Rancho Palos Verdes, Calif. 90274
(213) 378-3995

Computer Learning Materials, Inc.
P.O. Box 13325
Ann Arbor, Mich. 48103
(313) 996-1619

Brain-Link Software
317 Montgomery
Ann Arbor, Mich. 48103
(313) 995-0604

UCLA Intervention Program
1000 Veteran Avenue Room 23-10
Los Angeles, Calif. 90024
(213) 825-4821

DIL International Inc
2115 Bolvin
Ste. Foy, Quebec,
Canada G1V 1N6
(418) 687-9788

Dunamis, Inc.
3620 Highway 317
Suwanee, Ga. 30174
(404) 932-0485

Edu-Ware Series, Inc.
22222 Sherman Way, Suite 203
Canoga Park, Calif. 91303
(213) 346-6783

Hartley Courseware, Inc.
Dimondale, Mich. 48821
(517) 646-6458

Life Science Associates
1 Fenimore Road
Bayport, N.Y. 11705
(516) 472-2111

Midwest Publications
P.O. Box 448
Pacific Grove, Calif. 93950
(408) 375-2455

Psychological Software Services
P.O. Box 29205
Indianapolis, Ind. 46229
(317) 291-5909

REWARDING
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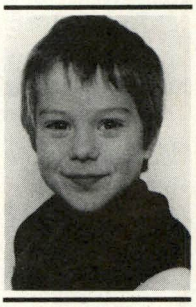

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Robert J. Sbordone, Ph.D.
13412 Donegal Drive
Garden Grove, Calif. 92644
(714) 638-1728

Sublogic Communication Corp.
713 Edgebrook Drive
Champaign, Ill. 61820
(217) 359-8485

Milliken Publishing Co.
1100 Research Blvd.
P.O. Box 21579
St. Louis, Mo. 63132-0579

Broderbund
P.O. Box 12947
San Rafael, Calif. 94913-2947

Activating Children Through Technology (ACTT)
27 Horrabin Hall
W. Illinois University
Macomb, Ill. 61455
(309) 298-1014

Learning Company
6493 Kaiser Drive
Fremont, Calif. 94555
(415) 792-2101 or
1-800-852-2255

MarbleSoft
21805 Zumbrota N.E.
Cedar, Minn. 55011
(612) 434-3704

MECC
3490 Lexington Avenue N.
St. Paul, Minn. 55126
(612) 481-3640

Thinking Works
P.O. Box 468
St. Augustine, Fla. 32085
(904) 824-0648

Teacher Support Software
P.O. Box 7130
Gainesville, Fla. 32605
(904) 371-3802 or
1-800-228-2871

Mindscape, Inc.
3444 Dundee Road
Northbrook, Ill. 60062

Springboard Software, Inc.
7808 Creekridge Circle
Minneapolis, Minn. 55435
(612) 944-3915

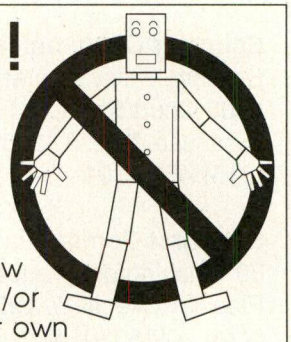
TOYS AND ADAPTED DEVICES

How to Modify Toys and/or Adaptive Devices:

Augmentative Communication Assessment Resource,
Goossens, C. and Crain, S.
Don Johnston Developmental Equip.
900 Winnetka Terrace
Lake Zurich, Ill. 60047

There is a wealth of information in this two-book series (the other volume is *Augmentative Communication Intervention Resource*). See pp. 140-144 for instructions on battery adaptations.

No More ROBOT Voice for Me !!!



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For additional information or to order, please contact:
Institute on Applied Rehabilitation Technology
The Children's Hospital, 300 Longwood Avenue, Dept. EP,
Boston, MA 02115, (617) 735-6466

Homemade battery powered toys and educational devices for severely handicapped children,
More homemade battery devices for severely handicapped children with suggested activities., Burkhart, L.
Linda J. Burkhart
8315 Potomac Ave. or
8503 Rhode Island Ave.
College Park, Md. 20740

Guidelines for Adapting Toys for the Physically Handicapped,
Higgins, J.
Jayne Higgins
California Avenue School
215 W. California Avenue
Vista, Calif. 92083

Homemade Switches and Toy Adaptations for Early Training with Non-Speaking Persons, Coker.
William B. Coker, Jr.
Cincinnati Ctr. for Dev. Disabilities
3300 Elland Avenue
Cincinnati, Ohio 45229
(Also published in *Language Speech and Hearing Services in the Schools*, 15(1), pp. 32-35.)

Toy Modification Note:
Build-it-Yourself-Battery-Insert,
Vanderheiden, G.
Trace Center
1500 Highland Avenue, S-151
Madison, Wis. 53705

Touch Toys and How to Make Them
(primarily toys for blind)
Touch Toys
P.O. Box 2224
Rockville, Md. 20852

Simple switch modifications for use in augmentative communication
Casby, M. (1984)
Refer to *Language, Speech and Hearing Services in Schools*, 15(3), 216-220.

Switching Mechanisms for Special Needs — A Project Manual,
Lynn, W.
National Clearinghouse of Rehabilitation Materials
115 Old USDA Building
Oklahoma State University
Stillwater, Okla. 74078
(405) 624-7650

Technology for Independent Living Sourcebook, Enders, A. (ed.)
RESNA
1101 Connecticut Avenue, Suite 700
Washington, D.C. 20036
(202) 857-1199

From Toys to Computers: Access for the Physically Disabled Child (1985),
Wright, C. and Nomura, M.
Christine Wright
P.O. Box 700242
San Jose, Calif. 95170

Adaptive play for special needs children: Strategies to enhance communication and learning (1985),
Musselwhite, C.
College-Hill Press
4284 41st St.
San Diego, Calif. 92105
1-800-854-2541

Organizations and Associations:

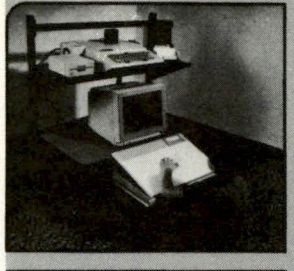
LEKOTEK
613 Dempster
Evanston, Ill. 60201
(312) 328-0001

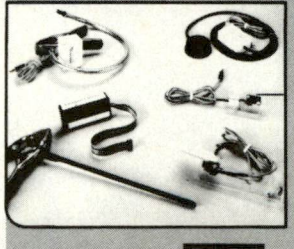
USA Toy Library Associations
1800 Pickwick Avenue
Glenview, Ill. 60025
(312) 724-7700
(Information plus newsletter)

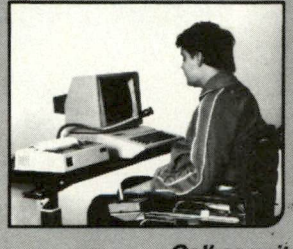
ACTIVE
Play Matter/NTLA
Seabrook House
Darkes Lane
Potters Bar, Herts, ENGLAND
EN6 2HL

This Resource Section is excerpted from The Northeast Communication Enhancement Group's Fall 1988 Newsletter, which included a more extensive listing. Write to NECEG, Box 241, Winchester, Mass. 01890, for more resource information.

The Handicapped's Source®







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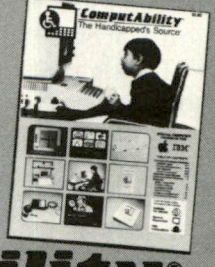

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GETTING IN & OUT OF YOUR HOME

Ramps, Elevators, Lifts and Doorways

Making Your Home Work is a new department that will focus on informing parents about adaptive aids and other kinds of equipment to help children get around and enjoy life as much as possible.

RAMPS

Since few homes or apartments are accessible at ground level without stairs or thresholds, ramping can be a big help. In selecting the best place for an entry ramp to a home, convenience, adequate outdoor space, and ease of maintenance are key considerations. Ideally, a ramp would be sheltered from bad weather; or, at least, protected from the "side effects" of bad weather such as snow falling from a roof onto the ramp.

The slope of a ramp, the relationship between the length of the ramp and the height of the ramp, is critical. The generally accepted ratio for slope is 1:12; that is, for every one foot of height, a ramp must extend 12 feet so that the slope will be reasonably gentle. A longer extension makes the climb even easier so a ratio of 1:14 may be better — if there is enough space at the entrance to the home. In fact, if the ramp rises more than two feet, a slope of 1:20 is likely to be much easier. However, when space is very limited, a steep slope of 1:8 may be workable.

A stair lift from National Wheel-O-Vator Company

When the amount of outdoor space is limited, a ramp can be built with the proper slope by using "L" or "U" shaped turns (called switchbacks). When this is done, it is usually helpful to have a landing at the switchback (turn) as a rest area. It is suggested that landings be level and at least 48" in each direction.

Landings for rest are also recommended on long straight ramps. For every 30 inches of rise, a landing 36-42" long is usually suggested. Landings can also be helpful at the top and bottom of a ramp. These should provide sufficient level space to turn, maintain balance, and open the door. Sometimes, at the end of the ramp, where it is likely to meet an already constructed structure, a so-called safety curb may be helpful for a smooth transition.

The width of the ramp depends on needs of the individual and on the mobility aid used. For example, if a child

Telescopic Channel Ramps made by Lakeshore Products

was learning to walk with crutches needing an adult alongside for assistance, a ramp would need to be rather wide.

For a person in a wheelchair, the individual's ability to control the chair and how much leeway is needed from side to side both contribute to determining sufficient width. Based on "typical wheelchairs," a width of at least 36" or more, up to 40-44", is usually suggested. A narrower width (30") may sometimes be adequate.

When the child is going to use handrails to help propel himself up the ramp, then steady and secure handrails on both sides of the ramp are needed and the distance across from one rail to the other must be measured carefully. This distance will be narrower than the ramp and will depend on the personal comfort of the child. The handrails can be square or round in shape, with round being preferred if the child is going to be holding on most of the time.

A small curb (at least 2" high) along the sides of the ramp will prevent the chair from slipping off the sides. If small children are likely to use the ramp, sides or some protective material along the sides can prevent falls.

The surface texture of a ramp should be designed to minimize slipping in wet weather. If the ramp is wooden, the wood planks should run across the ramp rather than up and down. If the ramp is concrete, it should be textured. Metal ramps are designed to minimize slipping.

Concrete ramps are permanent while metal and wood can be considered semi-permanent. Commercially available ramps come in sections of various sizes that can be dismantled, called modular ramps. All ramp materials should be fireproof.

PORTABLE RAMPS

Two kinds of ramps are portable and can be moved from place to place. Depending on the skills of the individual who needs the ramping, another person may be needed to set up the portable ramp.

Portable standard ramps are narrower (usually 26" wide) than permanent ramps and are usually hinged in the center for folding and have handles for carrying. The length of these ramps can vary from 30" to 10 ft and are of various weights depending on the materials used. Smaller sections can be bolted together for longer distances and adjustable support legs can be used at the connecting points of separate sections.

Track or telescoping ramps consist of two separate channels for the wheels of a wheelchair. Channels come in various lengths and are usually hinged for folding and carrying. Sometimes the channels telescope into each other for ease of transport. There have been some efforts to attach telescoping ramp channels directly to wheelchairs so that the individual can bring his or her own ramp.

Portable ramps may need rails, curbs, or landings depending on how they are to be used.

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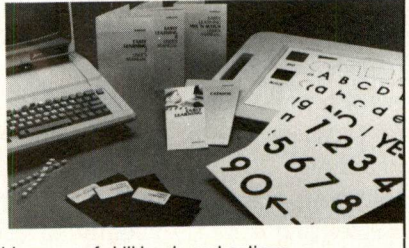

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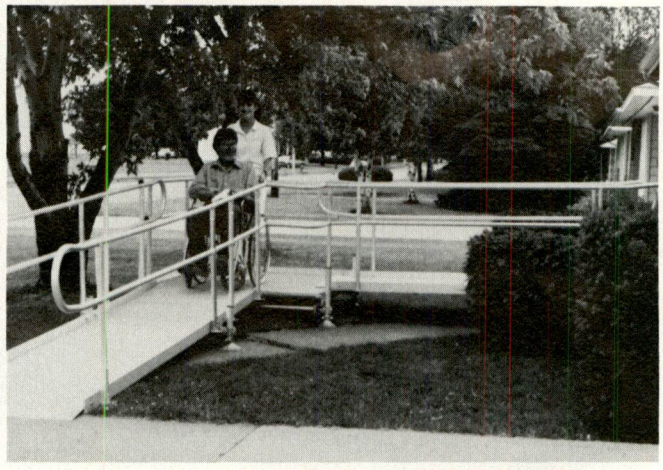

Ramping system with ANSI-approved handrails made by Lakeshore Products.

LIFTS

People and wheelchairs can also get to an entryway via an outdoor lift or elevator. Stairlifts and elevators can also be used indoors.

Stair elevators or vertical lifts may be in an encased shaft (elevator) or can be open, fitted onto guide rails or wall tracks. These devices can provide access to a porch or can be placed alongside steep stairs. They can also be used indoors if there is sufficient space in stairwells. Enclosed elevators need sufficient lighting and may need a communication device, like a telephone, in case of trouble. Special lifts are available to provide entry to a motor home.

Stairlifts are usually designed for straight stairways inside a home. Stairlifts are platforms with various types of seating (or standing), supports, and controls. The platform travels up and down the staircase on tracks on the stairs themselves or on the adjoining wall. Some are designed for the person to be seated on the lift itself; others can accommodate a person in a wheelchair. If a stairlift only accommodates a seated person, the ease of transfer from the child's wheelchair to the lift needs careful assessment.

Stairlifts, while expensive, are likely to be a less costly alternative to bedroom and/or bathroom access than creating a bedroom and full bathroom on a ground floor. If a home has two sets of stairs, two lifts are probably needed. Curved rails for staircase turns are available. Stairlifts should not use all the room on stairways.

Lifts should provide smooth rides, without jerkiness, and be easy to operate. Safety belts and gates are probably needed as is sufficient room at the top and bottom of the lift to exit or enter safely. Finally, lifts, like any powered equipment, are subject to power failures so some safety mechanism should protect the rider in such an emergency.

PROFESSIONAL INPUT

Members of a child's clinical team can help parents review the possible aids that are available and discuss how each product might help meet a child's current needs as well as the child's probable future needs.

The team can also share its knowledge about where products can be purchased, as can help identify other families who are using the same or similar products. In addition, the team can suggest adaptive equipment professionals (sometimes called medical equipment dealers, or just dealers) who may be able to help by demonstrating products, explaining the pros and cons of various choices, and sharing their wisdom about how to finance the purchase of specific products.

Key questions for parents and the team to discuss are how the child can get around now and what the future might look like. For example, can the child walk with crutches or a cane, or is the child likely to need a stroller or wheelchair for mobility? For children who will need a chair, who or what will provide the push power? Can the child learn to wheel himself or herself using his/her own strength, or will he/she need a motorized system? Or will the child need the help of another person to push the chair?

These questions are complex ones because the answer can depend a great deal on the specific setting being discussed. For many children, the answer may be that the child can learn to move the chair either by his/her own power or motor power and, sometimes, parents or others may need to help. Overall, the decision to purchase any equipment requires careful discussion and, whenever possible, opportunities to try before you buy and/or review with other consumers using the product.

Stair tracks are a completely different way to get a person in a wheelchair up stairs. The person in the wheelchair is wheeled onto the tracks (and frame). With another individual at the controls, the stair track climbs the stairs. Stair tracks can be battery operated and portable.

DOORS, DOORWAYS

Once a person in a wheelchair, or walking with crutches or cane(s), reaches the top of the stairs to a home, the door needs to be opened. For a person in a wheelchair to get through a doorway, an opening of at least 30" is essential. To accommodate a wheelchair propelled by a person's hands, with sufficient room

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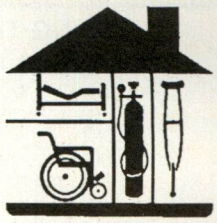

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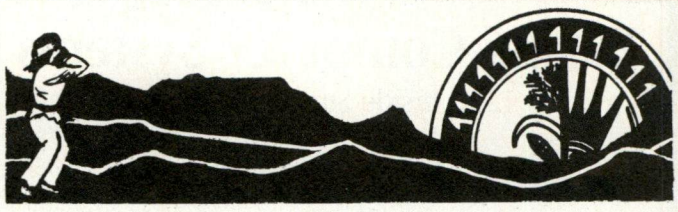

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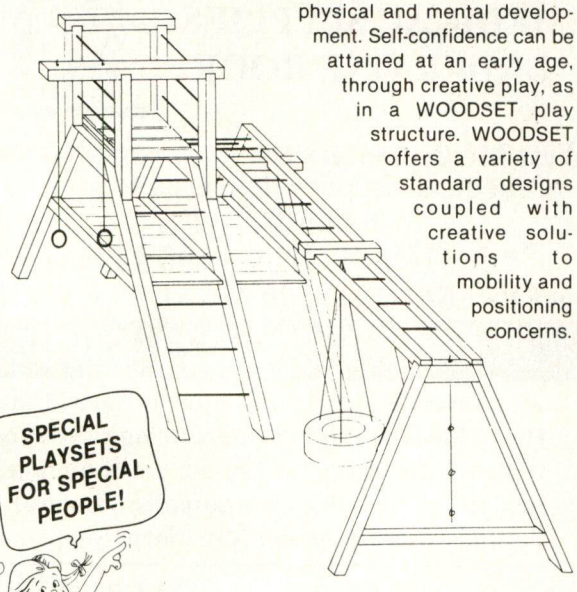

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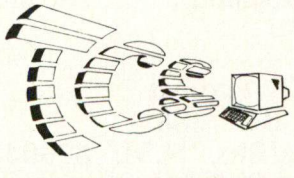

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The Stair-Trac made by Garaventa Ltd.

for both arms and elbows, usually requires 36", based on studies of average sized adult wheelchair users.

Interior doors which are often 32" wide may be sufficient. However, doorway widths can be deceiving because when a door is swung open, a few inches of width can be lost. Special hinges that allow a door to swing completely open can solve this problem.

Another consideration is which way a door should swing open to offer the best amount of clearance space. Spacewise, a sliding door can be ideal as long as the channel for the bottom runner of the door is set in the floor so it does not become a barrier.

Special handles can make a door easier to open than dealing with round doorknobs. Heavy rubber bands or nonslip strips can make round doorknobs easier to turn. In addition, a door may need a special handle to help the person close the door once through the doorway. For the person in a wheelchair, doors probably need kickplates since the person is likely to push the door with the metal footrests of the wheelchair.

At entry doorways, a shelf for packages or

bookbags will be helpful as will a handy light switch. Doormats need to be recessed or out of the way. Whenever possible, entry doorways should be covered to provide weather protection. Storm doors can add additional complications since two doorways close together must be managed. As a result, some people in cold climates use a single heavier door instead of storm doors.

Thresholds, or doorsteps in any doorway, can be an extra problem. It may be necessary to construct a wooden wedge; or a doorstep ramp can be purchased.

This article was prepared with the help of the following people: Melody B. Dill, President, Rehab Marketing Management, Milwaukee, Wisconsin; Terry B. Grall, Ph.D., President, Consumer Care Products Inc., Sheboygan, Wisconsin and Elaine Trefler, O.T.R., M.Ed., Director of Educaton, Rehabilation Engineering Program, University of Tenn., Memphis.

We would also like to thank ABLEDATA for assistance in developing the list of companies included in this article. ABLEDATA is a database with over 15,000 products useful to persons with disabilties from over 1,900 companies. ABLEDATA is funded by the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education.

Further information is available from ABLEDATA, Adaptive Equipment Center, Newington Children's Hospital, 181 East Cedar Street, Newington, CT 06111, (800) 344-5405 or (203) 667-5405 (CT) voice ot TDD. Reports are free up to eight pages (approximately 24 product reports). There is a nominal cost for longer reports.

A sample product printout from ABLEDATA is shown below.

Doc Number: 014478.
Generic Name: CURB RAMP.
Brand Name: WHEELCHAIR CURB RAMPS, F70610 0000, F70610 0001.
Manufacturer: Maddak Inc, 6 Industrial Road, Pequannock, NJ 07440.
Code Number: 0184.
Availability: Manufacturer.
Cost: $205.50 (folding); $175.50 (rigid), 1987.
Description: Wheelchair curb ramps available in single 36 inch length (F70610.0000) or 36 inch folding type (F70610.0001). Overall length of folding unit is 24 inches including carrying handle, 5 inches wide, 1 3/8 inch high safety edges. Made of polyester fiberglass. Double crossbars keep ramps aligned at 22 inch centers. Ribbed rubber treads improve traction. Rubber pads on the bottom of both edges prevent slippage. Maximum rise of 4 inches recommended.
Keywords: Architectural Elements. Vertical Lift. Ramps.
Comments: This category contains remarks regarding products and may not appear on every product entry.

The following pages list companies that manufacture the types of equipment discussed in the article.

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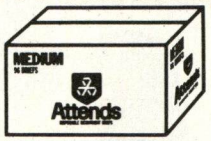

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Eligibility for Services for Persons with Specific Learning Disabilities

The following is an excerpt from a position paper on the eligibility for services for persons with specific learning disabilities which was approved by the ACLD Board of Directors and the Delegate Assembly.

PREAMBLE

ACLD recognizes that twenty years have passed since the condition or Specific Learning Disabilities was defined in federal legislation as a handicap. Today, there are still serious questions concerning Specific Learning Disabilities. These include etiology, incidence, diagnostic and identification procedures, eligibility criteria for services and continuation of services, and types and intensity of services.

ACLD's position is that Specific Learning Disabilities is a lifelong handicapping condition and once validly diagnosed, the existence of this handicap need not be questioned again. While the manifestations of the condition may change over time, the inherent condition persists. Reassessment is needed to monitor progress and develop appropriate plans but is unnecessary to verify whether an individual has Specific Learning Disabilities.

ACLD believes that both the individual and the family have a right to know when the Specific Learning Disabilities condition is suspected or diagnosed and the right to full information from diagnostic studies even when there is no immediate need for special services.

PART I: THE SPECIFIC LEARNING DISABILITIES CONDITION

Specific Learning Disabilities is a chronic condition of presumed neurological origin which selectively interferes with the development, integration, and/or demonstration of verbal and/or non-verbal abilities.

Specific Learning Disabilities exists as a distinct handicapping condition and varies in its manifestations and in degree of severity.

Throughout life, the condition can affect self-esteem, education, vocation, socialization, and/or daily living activities.

Specific Learning Disabilities is not synonymous with underachievement.

The Specific Learning Disabilities condition is lifelong and pervasive in nature, and can selectively interfere not only with learning in school settings, but also with the attainment or maintenance of acceptable social skills, appropriate work, good family relationships, and even the activities of daily living. Since it varies in its manifestation, the Specific Learning Disabilities condition in some persons undermines social interactions in spite of the person's high level of academic attainment.

PART II: THE DIAGNOSIS

The diagnosis of the Specific Learning Disabilities condition requires **clinical judgment** derived from multiple data. No specific test, battery, nor formula can substitute for **clinical judgment**. The professional or team making the diagnosis is responsible for the judgment. To help ensure valid diagnostic decisions, appropriately trained professionals require extensive, clinical training with **this population**. ACLD believes strongly that the validity of the Specific Learning Disabilities diagnosis increases when the responsibility for making the judgment is placed with clinicians who hold advanced professional degrees in generally accepted fields and who have two or more years of clinical experience with the relevant age group of the Specific Learning Disabilities population.

In the public schools the determination of the Specific Learning Disabilities condition must be made by an interdisciplinary team under the regulations for P.L. 94-142. ACLD endorses the use of interdisciplinary teams.

When an individual has a handicapping condition, she/he has a right and a need to know it. In the case of Specific Learning Disabilities, the sooner the individual and her/his family are aware of the condition, the greater the likelihood that early intervention can lessen the effects of the Specific Learning Disabilities condition on her/his life. Schools are in a unique position to help ensure an early diagnosis of the lifelong condition and open opportunities for early and continuing intervention.

ACLD reiterates its position that the Specific Learning Disabilities condition selectively interferes with one's abilities; consequently, the **use of composite scores is inappropriate**. Thus a person with Specific Learning Disabilities may have one learning rate and level of performance for language arts; a second for math, handwriting, and logic; and a third for social competence. Similarly, composite scores within a single subject area may be inappropriate with many persons with Specific Learning Disabilities. The diagnosis must provide a full description of how the individual learns

and the types of learning that are affected by the condition together with intervention methods which can offset those areas of deficit. ACLD believes that it is often preferable that the diagnosis be made by an agency other than the one(s) to be accessed for services.

Once a valid diagnosis of the Specific Learning Disabilities condition has been made for an individual, the existence of a life-long handicap need not be questioned again. Acceptance of this statement should help clarify the issue that the diagnosis of the condition is a separate issue from the need for services.

PART III: ELIGIBILITY FOR SERVICES; INCLUDING ACCOMMODATIONS

Once a valid diagnosis has been made, the individual is eligible, and remains eligible, for services that are appropriate to his/her needs. **Some individuals with Specific Learning Disabilities may not require specialized services** beyond the provision of information about the condition and its effects, reasonable accommodations, and appropriate self-advocacy. Others may not require specialized services at all times or in all environments. Still others **will require extensive services** in order to have the opportunity to achieve independent living.

All individuals with the Specific Learning Disabilities condition are guaranteed certain rights, opportunities, and access under federal, state, and local laws, regulations, and programs. All such individuals are entitled to relevant information regarding programs, services, and rights.

PART IV: THE ASSESSMENT AND THE NEED FOR SERVICE

In order to determine the needs of the person with Specific Learning Disabilities at a particular time, in a particular setting, it is essential that a complete assessment be made. Such an assessment should be the basis of an individualized plan for services which sets clear and reasonable goals that can be accomplished in a timely manner. The assessment must take into account the inherent strengths and weaknesses of the individual and her/his levels of accomplishment.

The areas in which strengths and weaknesses are assessed should include, at least, personal and social competence, health and physical education status, communication and basic skills, all content areas, repertoire of learning strategies, competence in self-advocacy, capability for using alternative learning aids, and pre-vocational and/or vocational achievement.

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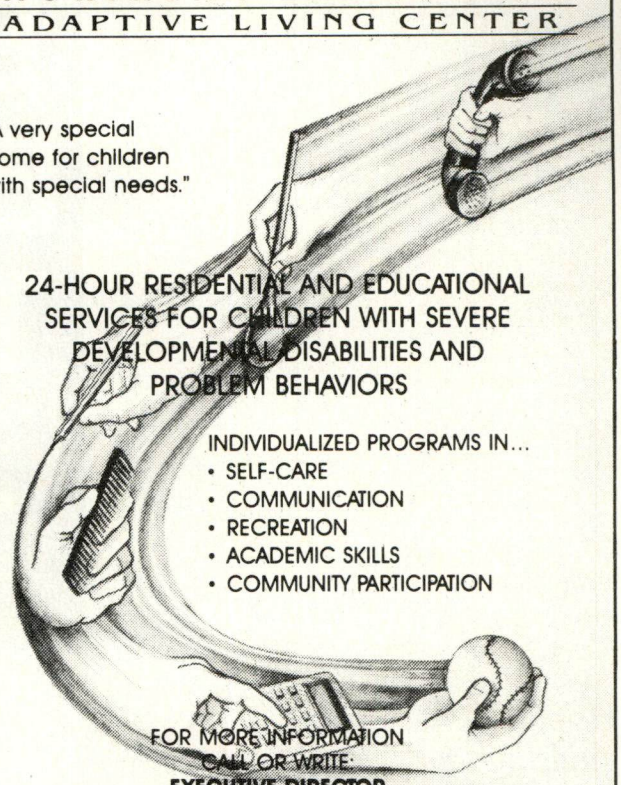

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BUT NOT ENOUGH TO TELL ◆ THE ◆ TRUTH

Developmental Needs of Siblings

Helpful guidelines for serving the needs of siblings.

by
Helen Stavros and
Richard D. Boyd

"Sometimes," offered Jenifer, "when I've done something that I know my parents are gonna yell at me for, I tell them Randy did it. Like when I forgot to flush the toilet and Dad yelled 'who forgot to flush the toilet!' I told him Randy did it. Then I went into my brother's room and told him what I had done. I felt guilty."

"Yeah," agreed Nicole, "that's like the time I broke the cookie jar in the kitchen. When Mom started yelling, I told her Jason did it. I felt guilty, but not enough to tell the truth."

Jenifer is a 10-year-old girl who has a twin brother, Randy, with Down syndrome. Randy has few verbal skills and frequently creates situations that are embarrassing for his three siblings, who are close in age.

Nicole, also 10, has a three-year-old brother with Down syndrome. While Nicole's brother has not yet embarrassed her through his behavior, Nicole finds it difficult to tell her friends and neighbors about his condition.

Nicole and Jenifer, along with four other children aged eight to twelve, had participated in a four-session workshop for siblings of children with special needs. The workshop was designed to help siblings express their feelings and concerns, and learn how to handle common, yet thorny situations. The children's parents participated in a separate group held concurrently.

The meetings covered material presented in the *Sibshop Manual* developed at the University of Washington, and in the book *Living with a Brother or Sister with Special Needs*. In particular, common conflict and problem situations that siblings might encounter were presented, and the children were asked how they would handle them. Time was also allotted to discuss disabling conditions, special education and simple behavior management principles.

The children expressed many feelings about their siblings with disabilities through role play, group discussion and sharing family stories. When asked to describe typical feelings, virtually all of the children listed embarrassment, pride and jealousy: embarrassment when they came

into contact with the world outside the family, pride when their sibling learned something new, and jealousy when their parents spent a disproportionate amount of time with their sibling with a disability. Envy was also mentioned by some whenever a sibling with a disability had little or no homework, few household responsibilities and fewer expectations placed on them by the parents.

The children proved to be knowledgeable and aware of what it means to have a sibling with a disability, benefitting from having open and informed parents. Yet it became apparent that these bright and forthright kids had great difficulty translating knowledge into appropriate and effective action. Their reactions were often based more on the feelings aroused by a situation than on what they knew to be the best response.

One 10-year-old girl, for example, told how she was unable to control her temper when her brother waved his hands in front of her face, even though she could clearly state that ignoring him was the best response. Others knew how to explain to friends or strangers that their brother or sister was disabled, but confessed that their performance broke down when they became embarrassed or angered by the ignorance and insensitivity of others. And one eight-year-old girl explained away her brother's delayed development by telling people he has a hole in his heart, even though she knew she was not being completely honest in doing so.

This gap between the knowing and the doing presents an interesting challenge for non-disabled children and their parents. As the children in this group clearly articulated, they felt guilty whenever they failed to respond in the way they knew to be best. Their parents, in turn, often became frustrated when they saw their non-disabled children "falling short." Yet it would be easy and foolish for parents to vent anger at the non-disabled child, as this would only increase that child's sense of guilt, foster resentment toward the sibling with a disability, and deny them the support and understanding they need to become more assertive.

Children in the preteen years commonly lack the ability to assert themselves, having been trained most of their lives to respect authority and avoid conflict. Those parents who recognize and understand the implications of this developmental stage will be in a better

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position to help their children become more assertive.

While non-disabled children need to know how to handle certain situations, they also need understanding from adults who can provide a forum for discussing what goes wrong and how to behave differently. Workshops provide one such forum, but the best and most enduring forum is created by open, honest and caring parents.

What can parents do to serve the needs of all their children? While any answer must, ultimately, depend upon individual circumstances, here are some guidelines that can prove helpful:

• Be sure that your expectations for your non-disabled child are realistic. It's easy to forget, sometimes, that they are children first, and we cannot expect them to handle difficult situations like little adults. For example, it would be unrealistic to expect a young child to be able to supervise, alone, a disruptive sibling while in public.

• Let your child know that you also get upset sometimes and often wish you could have been more assertive in a particular situation. Sharing an account of your own shortcomings can ease the sense of shame and guilt that the non-disabled child might feel over some incident of his own.

• Praise your child whenever she's done something of which you want to see more. Let her know specifically what it was that you liked, such as saying, "I liked the way you played with your brother today while I was fixing dinner."

• Don't expect too much too soon. Progress often comes in short, sometimes halting steps. Neither should you be surprised by occasional setbacks, being sure to give corrections in a gentle, positive manner.

• Keep the lines of communication open, paying attention to the feelings underlying what your child tells you. Let him know that his observations, concerns and suggestions are valued and worthy of discussion.

• Remember that the non-disabled sibling will have occasional negative feelings toward the child with a disability and that these feelings are normal and best approached with understanding and not with shame or guilt.

• Most importantly, show your child how you want him or her to behave. There is no substitute for a positive example, especially when it is coupled with the opportunity to practice appropriate behavior under the watchful eye of a warm, supportive parent.

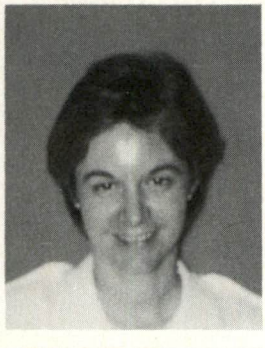
• Finally, help establish a sibling program in your community by encouraging organizations for the disabled, schools and early intervention programs to have a "sibling day" or to sponsor a sibling workshop. Parents can also establish informal sibling support groups through their own networks.

Having a child with a disability in the family is an opportunity for those living with that child to understand human differences in a way most people never get a chance to experience. Non-disabled siblings are in a position to teach others compassion and concern for those less fortunate. Furthermore, they have a chance to develop coping skills most children with siblings don't develop.

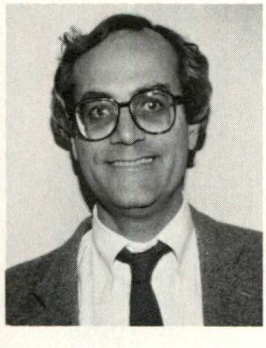
For that opportunity to be realized, however, these children need positive models and help from the adults in their lives if they are to learn to handle situations for which there are often no easy solutions. There will be many lapses between the "knowing" and the "doing," and the parent who understands this will be in a better position to help and will, ultimately, have competent and compassionate children.

The authors would like to thank John Hill, M.S.W., at the Education & Support Program at Children's Hospital in New Orleans for assisting in the development of the sibling program.

The Sibshop Manual and *Living with a Brother or Sister with Special Needs* by Donald Meyer, Patricia Vadasky & Rebecca Fewell are available from Exceptional Parent Library. To order, see page 67, under New Titles.



Helen Stavros received a master's in social work from Tulane University. She is currently a clinical social worker in the child psychiatry department of Ochsner Clinic in New Orleans, Louisiana.



Richard Boyd has a Ph. D in behavioral disabilities from the University of Wisconsin at Madison. He is working as a staff psychologist at the Golden Gate Regional Center in San Francisco, California, where he lives with his wife, Susan.

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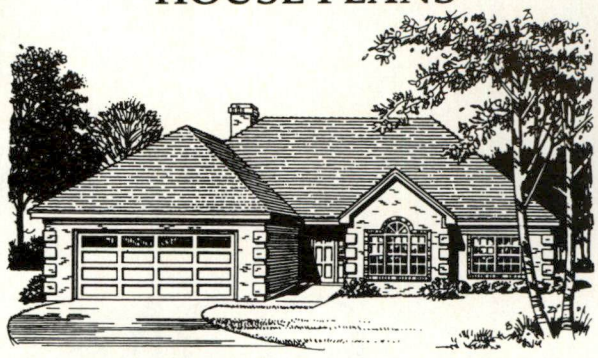

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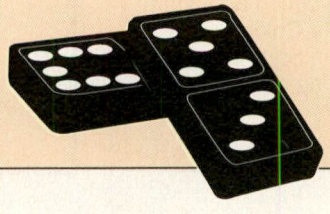
PEER COMPANIONS

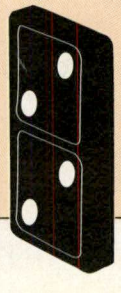
An Alternative to Summer Camp

by Ann M. Shannon

OUT OF A SERIES of good news/bad news scenarios, evolved a unique and rewarding summer program for our son, Eamon, soon to be 12, who happens to have Down syndrome.

In early spring, Eamon was invited to participate in his school district's summer program. It is a good combination of reinforcing basic skills in speech, reading and math, as well as important components of fun such as parades and celebrations that convey a camp-like spirit.





Eamon attended last year and enjoyed the experience. In late spring, Eamon's Annual Review Team made the decision that he had "abilitied out" of his placement in DLP (Developmental Learning Program) and now belonged in Cross Categorical (a program that offered more challenges academically). A side effect of this decision was that Eamon was no longer eligible for the summer program. That was the first good news/bad news scenario.

We applied immediately for SEASPAR, South East Association of Special Parks and Recreation in Illinois, a six-week nationally recognized summer day camp. Although we did not have first hand knowledge of the program, parents from our local Department of Special Education continually praise not only the creative slant but also the involvement of their children in these programs.

Eamon and Brian set up for the "Domino Spill."

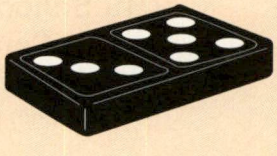
In early summer, Eamon was accepted. We were thrilled. Our excitement was short-lived, however, because we quickly learned that the Village of Western Springs, Ill., where we live, is not a resident member of SEASPAR. This meant, among other things, that Eamon was not eligible for transportation. UGH!!! The nearest child to us had grandparents who were willing to car pool. But that would have meant a travel time of one-and-a-half to two hours, depending on traffic. The more I thought about six weeks of rush-hour car pooling, the more my stomach churned. What were our alternatives? Should I cancel teaching a course, "Survey of the Exceptional Child for the Regular Classroom Teacher," at Chicago's St. Xavier College, 35 minutes in the opposite direction? Should the whole house be upset at dinner because one of us went to camp? This was the second good news/bad news scenario.

For a week we vacillated. What would be best for Eamon? What would be best for our entire family? Eamon has three siblings, aged 18, 17 and 15. We have a very busy active household.

One morning that lazy second cup of coffee helped me put a lot of pieces together. There were three essential components as far as we were concerned when it came to a summer program.

1). It should be fun.
2). It should be with age-appropriate peers.
3). It should offer an avenue for involvement in the larger community.

Given these components, the concept of a summer peer companion began to emerge. I phoned the mother of Brian, a 13-year-old boy who "babysat" for Eamon several times during the school year. She seemed excited about the possibilities of Brian's "job." (At this point all was so tenuous that the term "job" seemed a bit like an illusion of grandeur. We soon learned from the amount of Brian's paycheck given each Friday that



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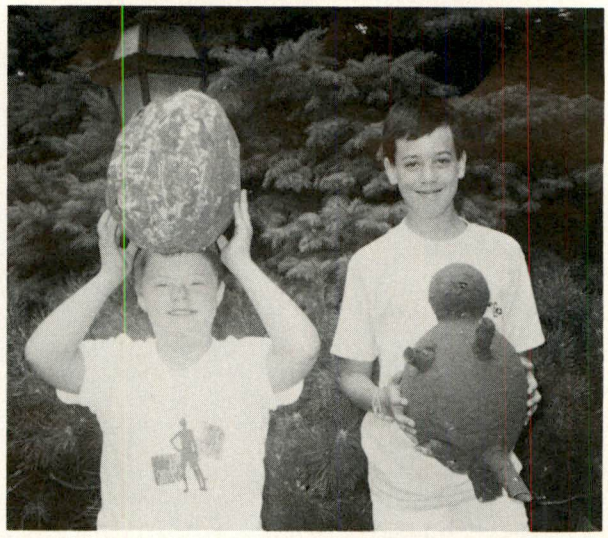


Eamon and Brian show their final art projects.

this was a real job.) Next, Brian and I spoke. Then Brian, Eamon and I spoke. We tried to define the ground rules. Everyone had input and everyone agreed to the following guidelines.

1). This was a paid position. Three dollars per hour was the fee. Brian was to buy a notebook and bring it each day. In this book he was to keep track of his hours and any other expenses. On Friday he would tell me his hours. (Incidentally, Eamon always checked to see if Brian had remembered the notebook.)

2). TV watching was unacceptable. In fact, this was the only non-negotiable.

3). Brian would teach Eamon various games and sports. Upon reflection these included Parchesi, Chinese Checkers, card games, magic tricks, basketball, volleyball and skateboard. At one point Brian asked his mother for new high tops for himself because Eamon was making more baskets. Brian figured high top shoes would make the difference.

4). Each day the boys had the option of walking to town, three blocks away, for lunch. Brian's parents own an ice cream and sandwich shop. A running account, settled weekly, alleviated daily counting out of money. It also gave the boys a freedom. Boland's Ice Cream Shoppe has a new hamburger as a result of these lunches, the Eamon Burger, replete with ketchup, mustard and mayonnaise. Brian couldn't believe that Eamon never deviated from that order . . . for an entire summer!

5). The boys would go to the library on alternate Fridays. Each afternoon they would select a book and read aloud, alternating pages.

6). The boys would attend the following activities at Kaleidoscope Children's Center, a section of our local Department of Recreation, which involves the children in "learning by doing":

Cardboard Carpentry . . . 3 sessions
Tie-Dye Shirts
Art Kids Love...Mothers Hate . . . 2 sessions
Domino Spill

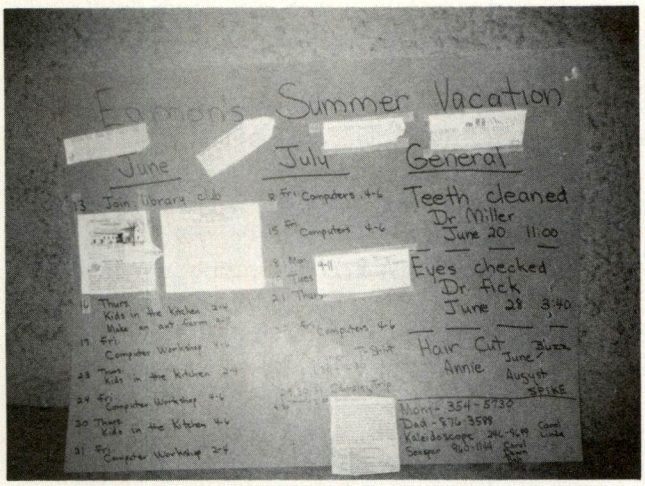
7). Brian would be responsible for walking with Eamon and picking him up after the classes only Eamon was taking. These included:

Building an Ant Farm (Big Problem . . . no ants!)
Kids in the Kitchen (3 sessions . . . Great Success)
Computers (4 sessions held on Friday afternoon late, too late)

8). The boys had the option of going swimming at the community pool. The great by-product was that Eamon learned the procedures to a tee. He knows exactly what to take and what is the correct behavior for a "cool dude," which enables him to get along with and be accepted by his peers at the pool.

To keep track of all these comings and goings we made a huge poster for Eamon's closet bulletin board. Each morning the boys would run upstairs to see what was on for the day. With very little guidance or supervision, they would decide on the day's doings.

A wise pediatrician once told me that parents only get points by hindsight. If that is true, then perhaps I should build into my day a lazy second cup of coffee. By all scales the summer companion program was a tremendous success. Brian's mother



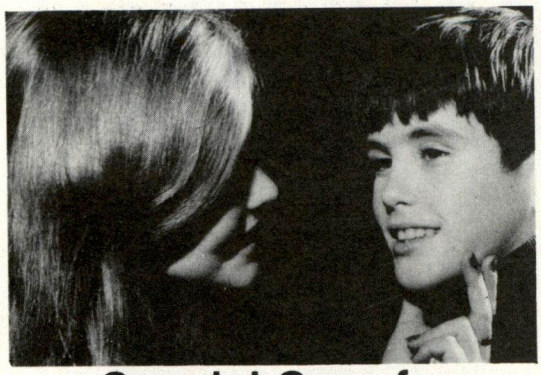
A huge poster kept track of all the summer's activities.

and I had lunch a few weeks ago to evaluate the summer. These were our observations.

Eamon, who has definite couch potato tendencies, was totally involved; by dinner he would be exhausted but exhilarated. He was in the community and part of the community all summer long. He wasn't there holding his mother's hand or standing by her side. He was there with one of the guys.

If Eamon used inappropriate language or responses, Brian would simply say: "Hey, Eamon, we don't do that." Amazing how behavior, good and bad, can be taught and caught.

In the process both boys became friends, though Eamon always introduced Brian as "my companion." He understood that Brian was paid to be his companion, but that didn't seem to be a problem because they had so much fun. They would spend lots



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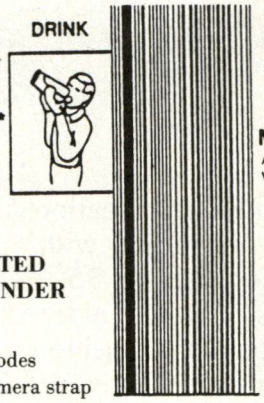

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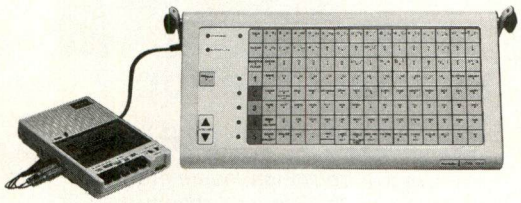

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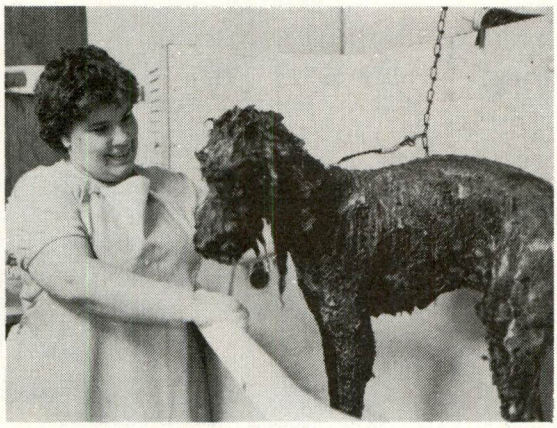

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of time in the drug store pondering which comic book to buy that week. The pharmacist told me the other day that he really misses the fellows and perhaps they could stop in soon.

The train sets came off the shelves and so did the boxes of Lego. Brian told his mom that he had forgotten how much fun some of these toys were and that he was glad to play with them again. After one of the classes, teasing about girls began. Both boys blush easily at the mention of a certain girl.

Initially Brian cautioned his mother: "Don't tell anyone." He was scared to death. He worried about the comments his peers would make when they saw him with Eamon. After the first day Brian was ready to quit. "You don't know what it's like to work so hard," he told his mother. Her response: "You are getting paid to work. You are seeing a part of life we haven't seen in our family. Someday, Brian, this experience might be part of your life work which is unknown to us now."

"Classes broke the ice," related Mary Boland. Brian, at 13, was the oldest participant. He didn't seem to mind because each event was structured at the individual level. Each worked at his own pace, all the while sharing and learning and caring.

Was this a one-way experience? I don't think so. A classmate of Brian's somewhat in awe told her mother about Brian Boland's great job.

The owner of our local family supermarket tells about watching two boys just being boys. "It's neat."

Brian's parents say he has become more self-confident. He engages in conversation more freely. He is very proud of his earnings and his purchases. He lights up when Eamon goes into Boland's for a snack or they meet unexpectedly on the street.

In late spring and early summer the good news/bad news scenarios were filled with ambiguity. How were we to know it would turn out to be a very special summer for two boys, their families and the community.

Anne Shannon received her master's in education from Trinity College in Washington, D.C. She is currently a lecturer at St. Xavier College in Chicago, where she teaches a survey course on exceptional children for the regular classroom teacher. Mrs. Shannon lives in Western Springs, Illinois with her husband, Peter, and their children, Peter, 19, Stephen, 17, Heather, 16 and Eamon,12.

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SUPPORT GROUP NEWS

In Touch With Kids is a network established by the National Spinal Cord Injury Association to help parents with similar experiences get in touch with each other. It is a support system intended to provide an opportunity for sharing ideas, feelings, resources and innovative problem solving techniques and solutions through telephone and written communication between families of children with spinal cord injury. NSCIA's quarterly magazine Spinal Cord Injury Life will feature a section to keep you "In Touch With Kids."

To become a member of NSCIA and get "In Touch With Kids," annual dues are $10.00. For more information contact NSCIA, 600 West Cummings Park, Suite 2000, Woburn, Mass. 01801. Telephone: (617) 935-2722 or 1-800-962-9629.

Sick Kids [need] Involved People, Inc. (SKIP) has announced the availability of a new family support handbook entitled, *Families to Families: The Home Care Experience.* Written by Karen A. Shannon, Karen Crawley Buckholtz and Linda Jennings, R.N., the handbook offers insight for new families who have children with disabilities who may need medical support management. Topics range from sharing initial feelings to answers resolving conflicts such as, "Is it my turn to help?"

The handbook is available through SKIP, Inc., 216 Newport Dr., Severna Park, Md. 21146 at $7.50.

The Treacher Collins Family Network is an emerging organization whose primary goal is to act as a support for and provide a network to families affected by Treacher Collins syndrome.

Due to the rarity of the syndrome, many families feel isolated and do not have the opportunity to meet another Treacher Collins child and discuss issues particular to this syndrome with another family. The Network hopes to bridge this gap.

The Network will not be affiliated with any hospital, craniofacial center, etc. The founders, Hope Charkins-Drazin and David Drazin, are parents of a young son with Treacher Collins syndrome, as well as being mental health professionals.

The Network is already a collaborative effort among families. Fifteen families from throughout the United States have already expressed an interest in participating. The first newsletter will be published soon, for which a mother has designed the logo and a family is researching and writing an article comparing different models of bone conductor hearing aides.

For more information and to join, contact: The Treacher Collins Family Network, P.O. Box 5, Concord, N.H. 03302, (603) 226-4371.

Families with children who suffer from Intractable Seizure Disorder are invited to join a new support group.

The founders hope to exchange information, request suggestions for special problems, keep each other abreast of the latest in research and technology, and in general allow each member to know that they are not alone. A newsletter for the membership is also planned.

For more information on the organization and newsletter, contact: Barbara Schwan, 29 Melrose Terrace, Middletown, N.J. 07748, (201) 957-0714.

The USA Sotos Syndrome Parent Support Group's next meeting is planned for July 22 & 23, 1989. The meeting will be in Arlington, Texas, close to Six Flags and other entertainment. There will be an invited speaker, and an interesting program is being planned. Parents and professionals interested in learning more about the history of Sotos syndrome are invited to attend.

For more information please contact Marilyn Brandon, Research and Education, Scott and White Clinic, 2401 South 31st St., Temple, Texas 76508, (817) 774-2350.

TRIPOD

TRIPOD is a non-profit organization committed to helping families raise their hearing-impaired children in an informed and positive way. Six years ago, parents, educators and community leaders dismayed by the confusion surrounding childhood deafness and the lack of quality education for hearing-impaired children joined forces and founded the TRIPOD school.

But children are not TRIPOD's only students. Parents, grandparents and family friends are welcome at TRIPOD and participate as volunteers, learn communication skills and get up-to-date information from the Grapevile, our national toll-free hotline. Medical and educational professionals are always on hand to answer questions and talk about concerns. Basic, fundamental information is provided so each family can make its own, informed decision as to what is best for their child.

The Tripod Grapevine is a national, toll-free hotline for anyone with questions about raising and educating a hearing-impaired child. In operation since 1983, this service handles more than 100 calls monthly. Nationally call 1-800-352-8888; in California call 1-800-346-8888. Both numbers are voice and TDD accessible.

SOCIAL SKILLS PUBLICATION

The National Information Center for Handicapped Children and Youth's (NICHY) News Digest No. 6 discusses "Social Skills." This short report offers insights into methods that have been used to change children's behavior and help them acquire social skills.

Write for the free booklet: NICHY, P.O. Box 1492, Washington, D.C. 20013.

AFB INFORMATION NETWORK

Need information on legislati ve issues affecting blind and visually impaired people? If so, the American Foundation for the Blind (AFB) has established the "AFB Information Network" to provide timely and accurate details on legislation and regulations of concern to blind and visually impaired people, their families and friends, and professionals in the field.

To enroll in the Network, write American Foundation for the Blind, Governmental Relations Department, 1615 M Street, N.W., Suite 250, Washington, D.C. 20036 or call Alan Dinsmore, legislative network coordinator, (202) 457-1495. You will receive a card listing a wide range of concerns, from aging and appropriations to transportation and voting accessibility.

Indicate on the card which issues interest you, and about six times a year the Network you will receive alerts targeted to the issues you selected. These alerts will briefly tell you what the legislation or regulation is, what advocates are doing about it, and specifically how you can be involved. If you notify the Network that you responded to an alert, you will receive a follow-up report that tells you the results of your advocacy efforts.

All alerts will be posted on popular databases including CompuServe™, 4-Sights™, SpecialNet™, and SCAN™.

NATIONAL DISABILITY ACTION CENTER

The National Disability Action Center (NDAC), a new civil rights advocacy organization headquartered in Washington, D.C., seeks to provide representation to persons with physical and mental disabilities who have been subjected to exclusion, segregation or any other form of discrimination.

The NDAC plans to identify incidents of discrimination stemming from thoughtlessness or prejudice against people with disabilities. "We plan to go wherever we are needed to rid this nation of disability discrimination," said Timothy M. Cook, founder and director of the NDAC.

The NDAC's first act was to file a class action suit in U.S. District Court in New York against the Long Island Railroad, alleging that it reconstructed four commuter rail stations without providing disability access. Federal and state law require that access must be provided when a station is rebuilt.

The suit contends that the entrances at each of the four stations were completely redesigned and rebuilt but remain inaccessible to people with physical disabilities.

Cook, 35, who has a walking disability, has advocated for disability rights for the past 10 years. He worked for the Civil Rights Division of the U.S. Department of Justice and also served as the executive director of the Western Center for Law and the Handicapped in Los Angeles. Most recently he served as deputy constituency director for presidential candidate Mike Dukakis.

Filed in February, the class-action suit also names the Metropolitan Transportation Authority and various officers and directors of the L.I.R. and the MTA as defendents.

For more information about the NDAC and its work, contact: Timothy M. Cook, Director, National Disability Action Center (NDAC), 2021 L St., N.W., Suite 800, Washington, D.C. 20036, (202) 467-5730 (Voice/TDD).

TECH-TAPES ANNOUNCEMENT

Effective March 31, 1989, the Center for Special Education Technology is no longer operating the TECH-TAPES message service.

When TECH-TAPES was introduced in late 1985, the Center's goal was to provide current information about technology and its use in

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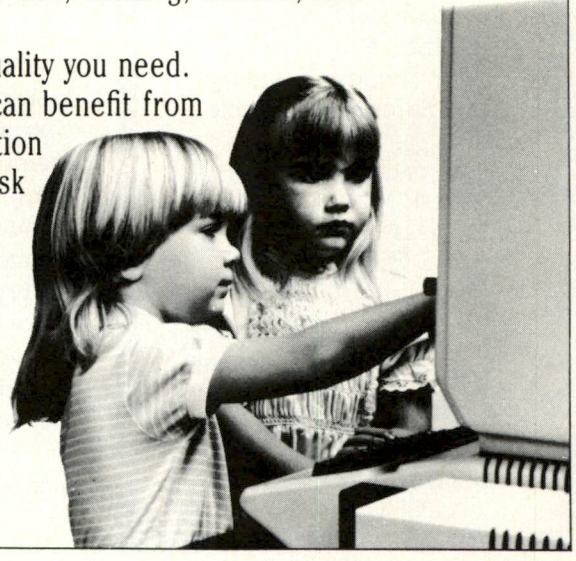

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special education. At that time there was a need for basic, introductory information about technology and few resources provided such information.

A recent assessment of the system showed that the information provided by TECH-TAPES is, in its present form, outdated. The service is no longer the source of current and timely information. The Center also recognized that the number of alternate sources of information has increased dramatically over the last three years. Basic information about technology and its use in special education is more readily available now than it was in 1985. As a result of these findings, the decision was made to discontinue the TECH-TAPES service this year.

The Center will continue to provide support to those seeking introductory information about the use of technology. Over the next three years, the Center will focus its development efforts on selected topics or themes within special education technology. New information products will be developed to address high interest topics. These will include state and topical "Resource Inventories" and a series of "Critical Consumer Reports."

The inventories have been developed to encourage wider use of existing information resources. The Center will produce a technology inventory for each state as well as inventories on specific subjects that will include national information.

The first six topical Resource Inventories available will be: assistive devices, augmentative communication, Apple Alliance members, Rehabilitation Engineering Centers, product availability resources and a general national technology inventory. In the future, the topical inventories may expand to cover disability specific technology as well.

The Critical Consumer Reports are fact sheets aimed at specific populations of special education technology users. The first three Critical Consumer Reports address the technology needs of teachers, parents and adults with disabilities.

Both the Critical Consumer Reports and the Resource Inventories are available by writing to: Center for Special Education Technology, 1920 Association Drive, Reston, Va. 22091.

HOUSING NEWSLETTER AND FINANCE GUIDE

The Housing Technical Assistance Project announces the publication of its guide to finance strategies, which is designed to increase opportunities for housing for people with disabilities. This free guide should be available in the spring.

The Project is a joint effort of the Association for Retarded Citizens and the National Association of Home Builders and its National Research Center to provide technical assistance in the financing and designing of housing for people with disabilities. The project is funded under a contract with the Department of Housing and Urban Development (HUD).

In addition to the publication of this guide, the project provides information and technical assistance and is publishing a free monthly bulletin with updates on project activities and current information on the design and finance of housing for people with disabilities. The bulletin is distributed upon request.

The Finance Strategies Guide will include tips on the housing development process, descriptions of funding mechanisms and profiles of some successful and innovative projects to provide housing options in integrated settings.

The guide focuses on the development of linkages among members of the nonprofit community, the housing industry and people with disabilities in order to address the need for affordable, accessible housing. Cooperation among these groups can help to ensure the development of workable projects spon-

sored by nonprofit groups, while also improving access to housing in the community and providing consumers meaningful choices.

For more information on housing issues, the Fair Housing Amendment of 1988, technical assistance in finance and/or design or to receive the free guide and/or bulletin, contact: The Association for Retarded Citizens, Governmental Affairs Office, Bill Mitchell, Project Coordinator, 1522 K Street NW, Suite 516, Washington, D.C. 20005 (202) 785-3388.

PALS ACROSS THE WORLD

Pals Across the World is an international computer writing project for students grade three and up. Now truly a worldwide system, the network began as the "Australaskan Writing Project," which matched a class in Fairbanks, Alaska, with students in a school in Australia.

The network matches students, some with special needs, from the United States, Canada, New Zealand, Great Britain, France, Germany, Sweden, Japan and South America to establish a fun and educational exchange between the countries.

International computer communication is possible through each country's electronic mail service. Participants simply send messages to another system through an international network of phone lines and satellite connections.

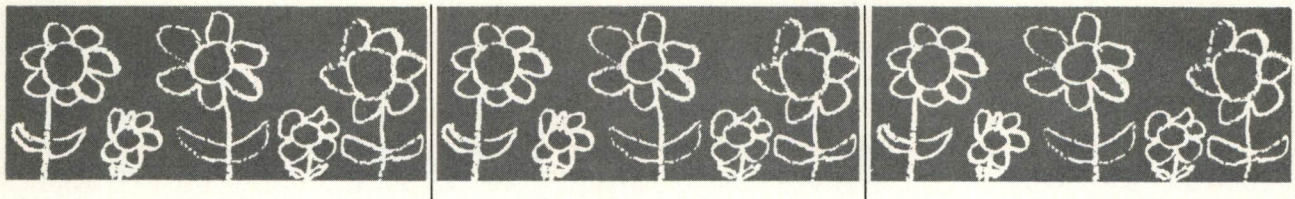
In the United States, Pals use the Dialcom electronic mail system, which is accessible through either TELENET, TYMNET or a national toll-free number. Any computer with a modem and telecommunications software can reach Dialcom.

A class of youngsters with physical disabilities in Great Britain is organizing a chess tournament by electronic mail, as well as natural and social history projects.

Currently, there are about 80 schools on-line, including some special education programs. Third and fourth grade classrooms are the most active users of the service, but some in-home private users are involved in Pals Across the World.

Users can choose international or domestic computer pals. Pals Across the World charges $5 a month for basic services, and costs average $30 a month for an active, international correspondence; domestic costs are significantly lower.

For more information about Pals Across the World, contact Jim Erwin, 4974 S.W. Galen, Lake Oswego, Ore. 97035, (503) 697-4080 or (503) 635-0338.



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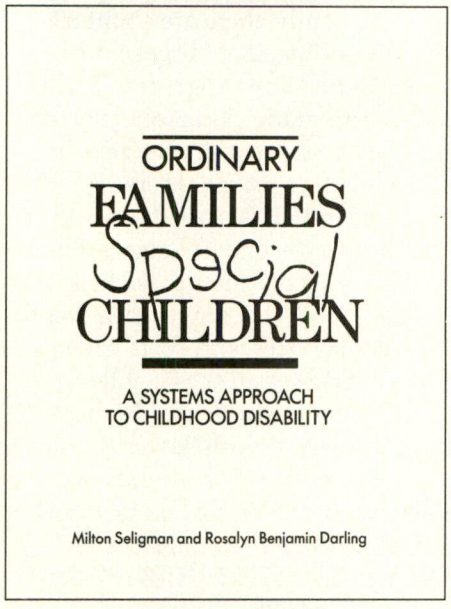


Ordinary Families, Special Children: A Systems Approach to Childhood Disability

By Milton Seligman, Ph.D. & Rosalyn Benjamin Darling, Ph.D.

The following excerpt from Chapter Six: Effects on Fathers and Grandparents *has been reprinted with permission from the publisher, Guilford Publications, Inc.*

Although we know little about how grandparents react to the birth of a grandchild with a disability, it is likely that they experience a mourning period for the loss of the idealized grandchild they had expected. Just as the parents experience the "death" of the expected normal, healthy child, so, too, may the grandparents feel a great loss and mourn the death of what they had wished for. They may go through the same stages as the parents: denial, grief, anger, and eventually acceptance. Reporting on the reactions of grandparents who attended the grandparents' workshops at the University of Washington, Vadasy and colleagues (in press) report that their initial reactions were most often sadness (67%), shock (38%), and anger (33%). Forty-three percent reported that they continued to feel sad long after they first learned of their grandchild's disability, but 57% expressed eventual acceptance of the problem.

Grandparents may be mourning at the same time as the parents. In the crisis-laden initial period of discovery, both the parents and the grandparents may be experiencing great loss and grief; they may therefore be unable to be supportive of one another. According to Gable and Kotsch (1981), grandparents may be in a state of "diminished capacity" for providing help to the child's parents. Whatever the initial reactions, professionals need to be cognizant of what different family members are experiencing so that they can take these reactions into account in counseling.

[W]e have suggested thus far that grandparents, through their lack of support, can be a source of considerable consternation to the nuclear family of a disabled child. The sense of threat and vulnerability, the loss they experience, the ambiguity the situation holds for them, their denial and lack of acceptance can indeed be burdensome for the family. However, perhaps for most families with a disabled child who have living extended family, the situation may be more positive. Indeed, as Vadasy and Fewell (1986) report, mothers of deaf-blind children ranked grandparents high on their list of supports.

Grandparent contributions to the nuclear family can be many and varied. For example, Vadasy and colleagues (in press) conceive of grandparents as valuable resources to their grandchildren and the rest of the family. Due to their experience, grandparents have much to offer in advising about child care, providing access to community resources, and in sharing coping strategies that helped them in the past. Because they also have time available, they can assist with shopping, errands, and child care; and any type of respite from the daily chores of caring for a disabled child is welcome. Respite services are not available in some communities, making this a most valuable contribution to the family. Furthermore, because of their community contacts grandparents may be able to provide the family with access to services within the community. For example, as noted by Vadasy and colleagues (in press), through the grandparents' church group, the family might gain access to child care, special equipment, and other types of support.

Perhaps the most important type of help from the extended family is emotional support. The support of grandparents during the initial diagnostic and "first knowledge" phase and throughout the child's development adds immeasurably to the parents' ability to cope, and it provides excellent role models for siblings as well.

"You think that after you've raised your children you can stop being a parent and become a person again. And then your adult child experiences tragedy or loss, and your heart aches with the knowledge of your own importance and how you yearn to go back to the days when a Bandaid and a kiss could fix anything. Who are we to try to advise our children? How can we see beyond the moment, how can we diminish their pain or give them our patience and our constancy, and try to keep our own hope alive" (Click, 1986, p. 3).

"From the very beginning, there was no question that she was accepted, just like any other child born in our family. I remember how the whole family rallied. They said that she would be fine, and it meant a lot to us to have that family support. They sent us cards and flowers and gifts and did all the things you do when a baby is born. And I think that was so important, because, after all, she was a baby first, and then a baby who had problems" (Vadasy et al., in press).

Grandparents can thus be a source of emotional support and instrumental assistance; but, as noted

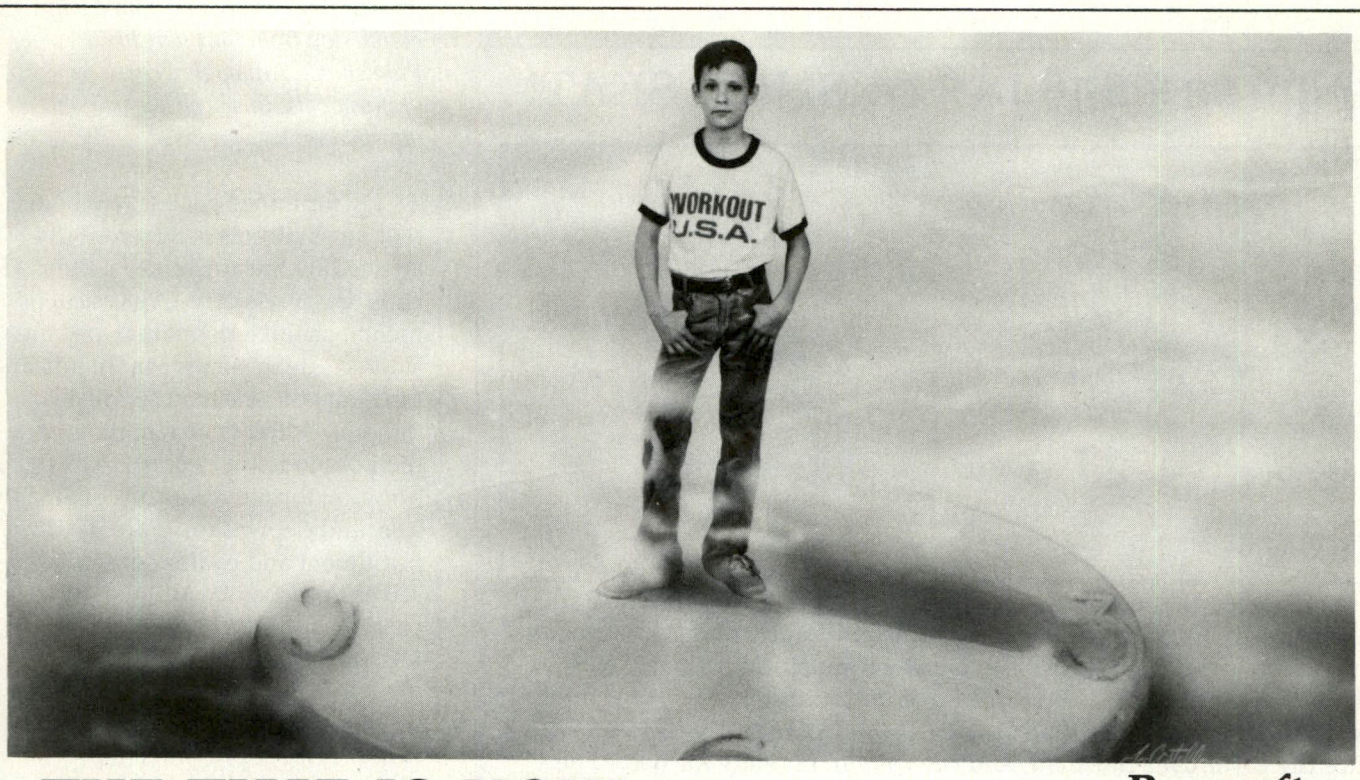
above, they can also add to the family's burden when they are not accepting of their grandchild and fail to be supportive. The question, then, is how professionals can help those grandparents who wish to be involved and useful as well as those who are struggling with their feelings and, as a result, find it difficult to come to terms with the family's crisis.

Vadasy and colleagues (in press) believe that grandparents have similar needs to those experienced by the parents, namely, support and information. Based on the notion that most grandparents want to be supportive and can potentially be helpful to the family emotionally and instrumentally, Vadasy and colleagues developed the grandparents' workshop model at the University of Washington in Seattle. The Seattle researchers believe that grandparents can add to family stress if they lack adequate information or have unrealistic expectations for their grandchild's potential. Conversely, they believe that access to accurate information can contribute to the grandparents' acceptance and resultant support.

From their research, Vadasy and colleagues (in press) found that grandparents were lacking in a number of areas. For example, they wanted to have more information on available therapies for their grandchild, know more about the child's disability, have some idea of what the child's potential might be, and the like. They often questioned whether they were doing the right thing with their grandchild and expressed concern about the future. Based on these and other concerns, the University of Washington grandparents' workshop model was developed (Meyer & Vadasy, 1986).

Another program sensitive to the needs of the extended family is the Family, Infant, and Toddler Project at Vanderbilt University (Gabel & Kotsch, 1981). The extended family component consists of bimonthly evening clinics for grandparents and other kin. During the clinics, therapies are explained, educational programs are reviewed, and a portion of the meeting is opened to questions. Gabel and Kotsch report that the relatives are more understanding and helpful after attending the family clinics. Sonnek (1986) reports on a number of localities that have extended their programs for disabled children to include nuclear and extended family members. Although the inclusion of the extended family in existing programs seems to be gaining more acceptance, there is little empirical evidence regarding these individuals' effectiveness in supporting the immediate family.

Based on the belief that grandparents are important resources and that their involvement benefits themselves as well as the nuclear family,



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we agree with Vadasy and colleagues (in press) when they remark that "all professionals would be wise to look more closely at the extended networks of the families in their programs to appreciate the contributions that extended family members, like grandparents, make, and to recognize and foster their concern for the child and family." Sonnek (1986) also supports this view when she states that "it appears the grand-parents, to date, have been an unrecognized and possibly an underutilized resource in the study of the nuclear family" (p. 108).

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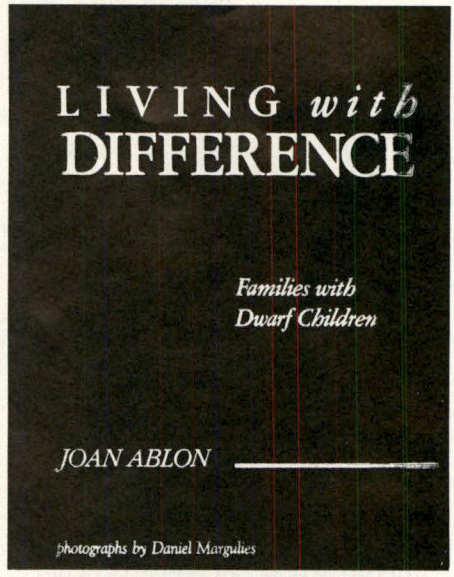

Living with Difference: Families with Dwarf Children

By Joan Ablon

The following excerpt from Appendix B: Impact of Child Disability and Physical Difference on the Family *has been reprinted with permission from the publisher, Praeger Publishers. Although written for professionals, this book has valuable information for parents.*

Cummings et al. (1966) noted that most parents are profoundly affected by the attributes of their children. Variations in physical or mental characteristics that are considered "deficiencies" or "handicapping" conditions may seriously influence parents' perceptions of their own identity and self-worth, bringing forth expressions of anxiety, loss, and depression. Parents' own fulfillment and evaluations of themselves thus may be at stake in the persons of their children and the normalcy for the family.

[I]n a remarkable study of the mothering of thalidomide children, Roskies (1972) presented a psychosocial working model for the presentation and analysis of her data. Stated Roskies:

> We formulated, then, a working model in which, basically, we

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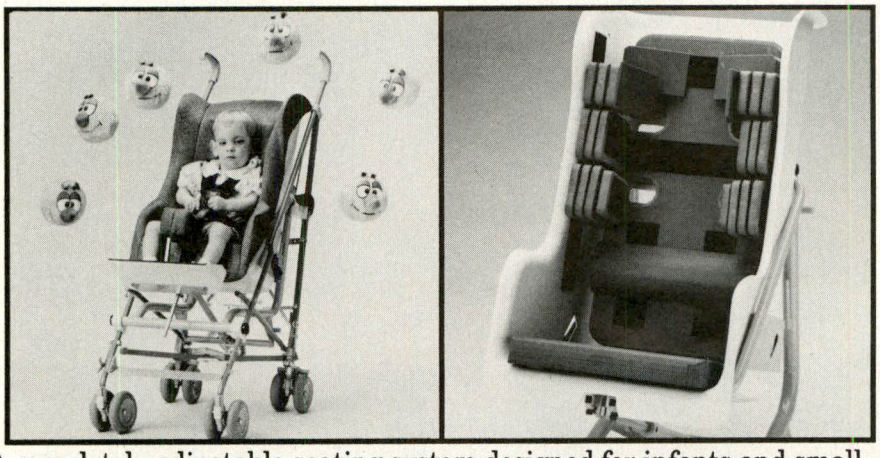

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hypothesized that the birth of an obviously defective child could create a very specific type of crisis. The essence of the crisis lies not only in the narcissistic injury to the parent, or the need to mourn the wished-for normal child (Solnit and Stark, 1961), but also in the fact that the existing child embodies a basic contradiction. To put it in its crudest terms, living children are taken home, caredfor, loved, and identified with, while dead children are buried. The child who is living but defective is an unknown combination of the two. Thus, immediately, the mother is confronted by the dilemma of deciding whether her child is normal enough to induce the mutuality of mother and child, or whether he is so defective that he no longer arouses the emotions and responses habitually aroused by a child. . . .

In common with mothers of all children, the course of development exacts a continuous process of adaptation and readaptation of a changing mother to a changing child. In this sense the rearing of a disabled child resembles the rearing of a normal child. But for the mother of the disabled child, the normal developmental crises are intermingled with an additional continuous crisis. The unclear and constantly changing amount of normality and abnormality embodied in the handicapped child makes the mothering of such a child an adventure in two different cultures. At times, the rules of the culture of normality are more relevant, while at other times the rules have to be taken from the culture of abnormality. Often it is difficult to predict in advance which would be most relevant. And frequently the choice involves an overt conflict between two equally valid but incongruent possibilities (pp. 20-21).

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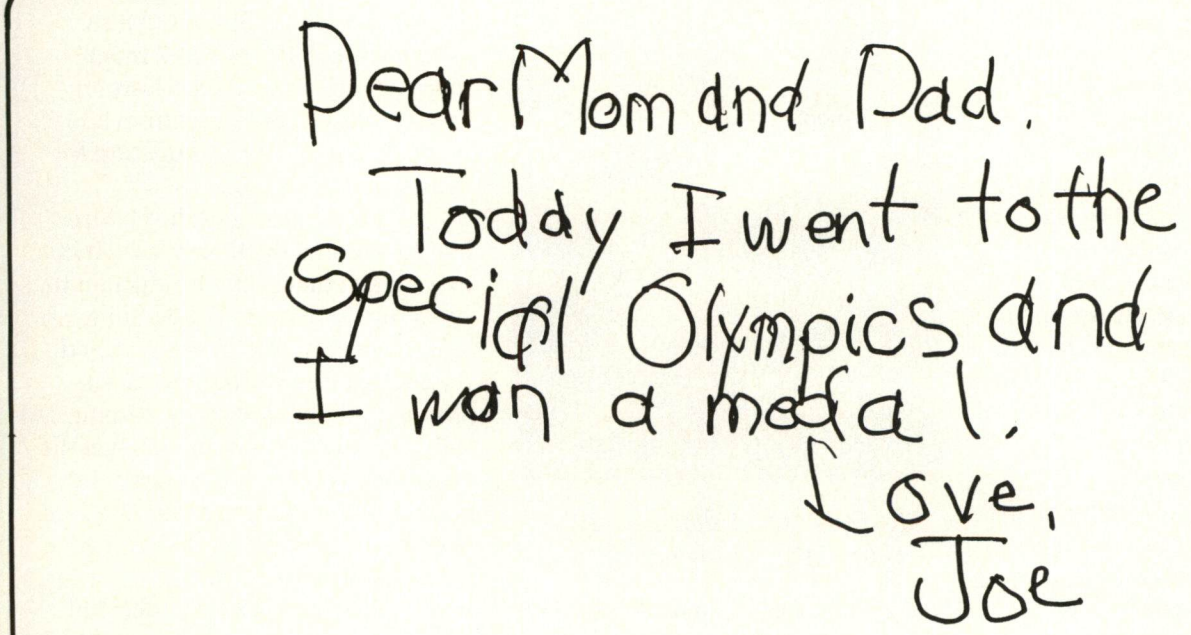

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"This has been a miserable fall."

Problems of Moving to a New Community

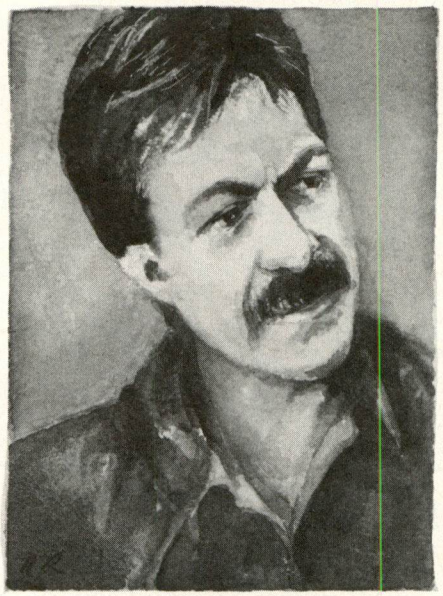
"This has been a miserable fall, and we really don't know what to do," Tim Charles explained. "Our nine-year-old son, Bill, is miserable in school. Bill has cerebral palsy; he is in a wheelchair. Also, when people first meet him, they may not understand everything he says. Since we have just moved to this town, Bill has started a new school. Ruth and I had mixed feelings about moving. I was promoted in my company about a year ago, but my new office was in a building in the next town.

"Billy was doing very well in the school that he was in, and we had a nice life in that community. We had grown up in the town; we had a lot of friends, and Billy was doing as well as we could expect. So we didn't move, and I commuted almost 100 miles a day. At the end of the year I was exhausted. It seemed to me I was spending more and more time on the road and less and less time with Ruthie and Billy.

"We had both heard good things about the schools in the town that we now live in. Supposedly they are excellent academically, and we heard they also have had some success with children with disabilities. So, we moved. I was more anxious to move than my wife.

"From Billy's first day of school there have been problems. He was reluctant to go to school the first day. Ruth spent a lot of time taking him to school and trying to reassure him. It wasn't clear to either of of us what was happening.

"At first we discussed the problem with Billy. He would just look sad and get teary. As unhappy as he seemed to be, it also seemed to me that he was learning a great deal. I just looked at the books he was bringing home and the work that he was producing. There is no question that this school system is much more demanding than Billy's previous school. But at the same time, his grades aren't as good. I thought that that was the reason for his disappointment. I spent a lot of time at night asking Bill if he wanted help with his homework. I was trying to assure him that we were happy with his school performance and we felt — or certainly I did — that sooner or later he would do better.



"Ruth is afraid that I would only make things worse."

"This didn't seem to help very much. So I suggested that Ruth talk to his teacher. That meeting only increased our concerns. Ruth said that Mrs. Abrams was understanding of Billy's struggle academically and explained that he was doing as well as any new child does in adjusting to a new school. She was described her efforts to reassure Bill. Ruth also noticed was that this was a much more openly-structured classroom than the school Bill came from and there are a lot of kids competing for the teacher's attention.

"In the old school the children had to wait to take their turns. In his new class, where Billy is reluctant to speak up, Ruth feels he is getting less than he needs. When she watched the playground during recess, she also noticed that kids were teasing Billy and that he was alone while the other kids were playing. Basically nobody was talking to Billy. And even in the classroom, she recalled, he sat by himself.

"About a week ago I decided that I should go take a look myself. We began to ask Billy about friends; he was in tears. He said that the kids in this town just were different. They didn't like him, and he would never be liked. I called Mrs. Abrams about the teasing and she seemed very resistant and I sounded resentful.

It was almost as if I was talking about something that would damage the image that they had of themselves as a school. I also noticed that the youngster next door doesn't play with Billy at all. Occasionally I've heard him mimic Billy's speech in the backyard.

"I think something should be done. I want to talk to our neighbor and I want to talk to the principal of the school, and I'm prepared to talk to whomever is necessary to make sure that there's more acceptance of Billy. Ruth is afraid that I would only make things worse. At the same time I don't want to move again. I'm happy with the house and the neighborhood and especially with the short commute.

"It's here where Ruthie and I disagree. Although she doesn't really say it, she spends a lot of time talking about the old neighborhood. I wish that she would begin to see something more positive about where we live. She also is much more reluctant to challenge what's going on."

"I don't think Tim understands either Billy or me." Ruth Charles, a short, somewhat chubby woman in her mid-30s spoke softly. "Tim is much more self-assured than I am. He is much more willing to speak his mind. He's happy with his work and things are easy for him.

"Until Billy was five, he didn't spend much time with him. Tim seemed to be much more depressed about Billy's progress than I was. But once Billy entered school and he began to show that he could learn, Tim's interest increased. So for Tim, the fact that this is a better school system and that Billy is doing more in school is pleasing to him.

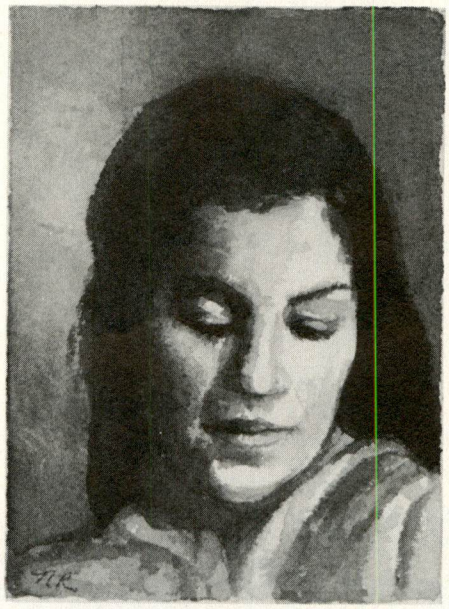
"The town that we grew up in was just simpler for all of us. We

Illustration by Natalia Raphael

knew we were destined to get married since we were in high school. We both have families and friends there. When Billy was born, there were a lot of people who we could turn to for help. Even during Billy's first year, when I don't know what really went on except that both Tim and I were so depressed, there just seemed to be somebody around all the time — his family or my family or our friends.

"As a result, Billy has always been around other people: kids, cousins, friends of ours. So when he started school, everybody knew he was coming. He even had the same first grade teacher that I had. Even though this woman is sort of old now, I knew her and she knew who we all were. So Billy really was accepted, and I certainly felt at home.

"I'm not sure that was as big a deal for Tim. We had long discussions about whether to move or not. I think if it wasn't for Billy we probably would have just moved without any trouble. But I still haven't found ways to fill my days. They just seem sort of empty. I worked part-time before we moved and I'm sure I could find part-time work again. I haven't been in touch with my old friends because it's a toll call to where we used to live; nobody's dropping by; nobody's coming by; and the few times we have visited it's a big effort to get Billy pulled together, get the wheelchair in the car and drive back.



"Tim is much more self-assured than I am."

"I'm not sure how often we've talked to our new next-door neighbors. I'm sure that doesn't help, because the next door neighbor — the kid — isn't very friendly. I'm not sure what to do.

"But I'm sure that going to the principal over Mrs. Abrams's head might just alienate her. And it might give us the reputation of being pushy. That isn't the way we would have done things before. I'm not really comfortable with doing it this way now."

The Charles family came because of their concerns about their nine-year-old son, Bill. Bill, a youngster with cerebral palsy, was having difficulty adjusting to school in their new community. Tim Charles believed that Bill was doing well academically and that his social troubles would resolve themselves in a period of time. Ruth Charles thought her husband focused so much on achievement that he didn't understand the daily struggle that Bill was having or how increasingly difficult things were becoming for her.

Mr. Charles felt that his wife was exaggerating their son's difficulties. They both agreed they had different views about their recent move. Mrs. Charles had been reluctant to move from the community where she had lived all her life and where she had a network of friends as well as professional contacts that had made her life and her son's life easier. Both felt stuck in terms of what needed to be done next.

Moving to new communities and starting new schools is a common phenomenon in the life of all youngsters. Almost 25 percent of all

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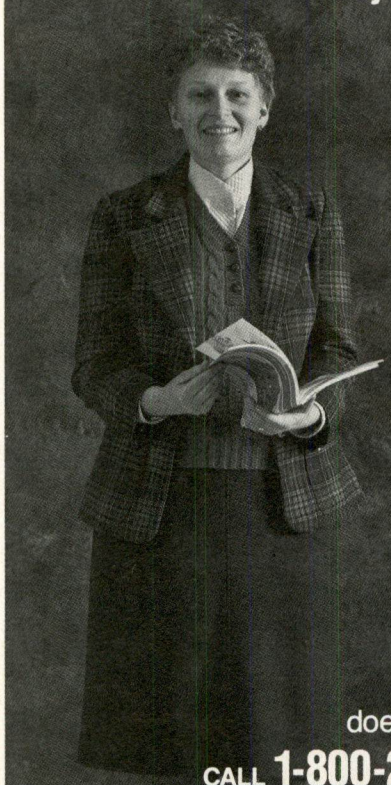

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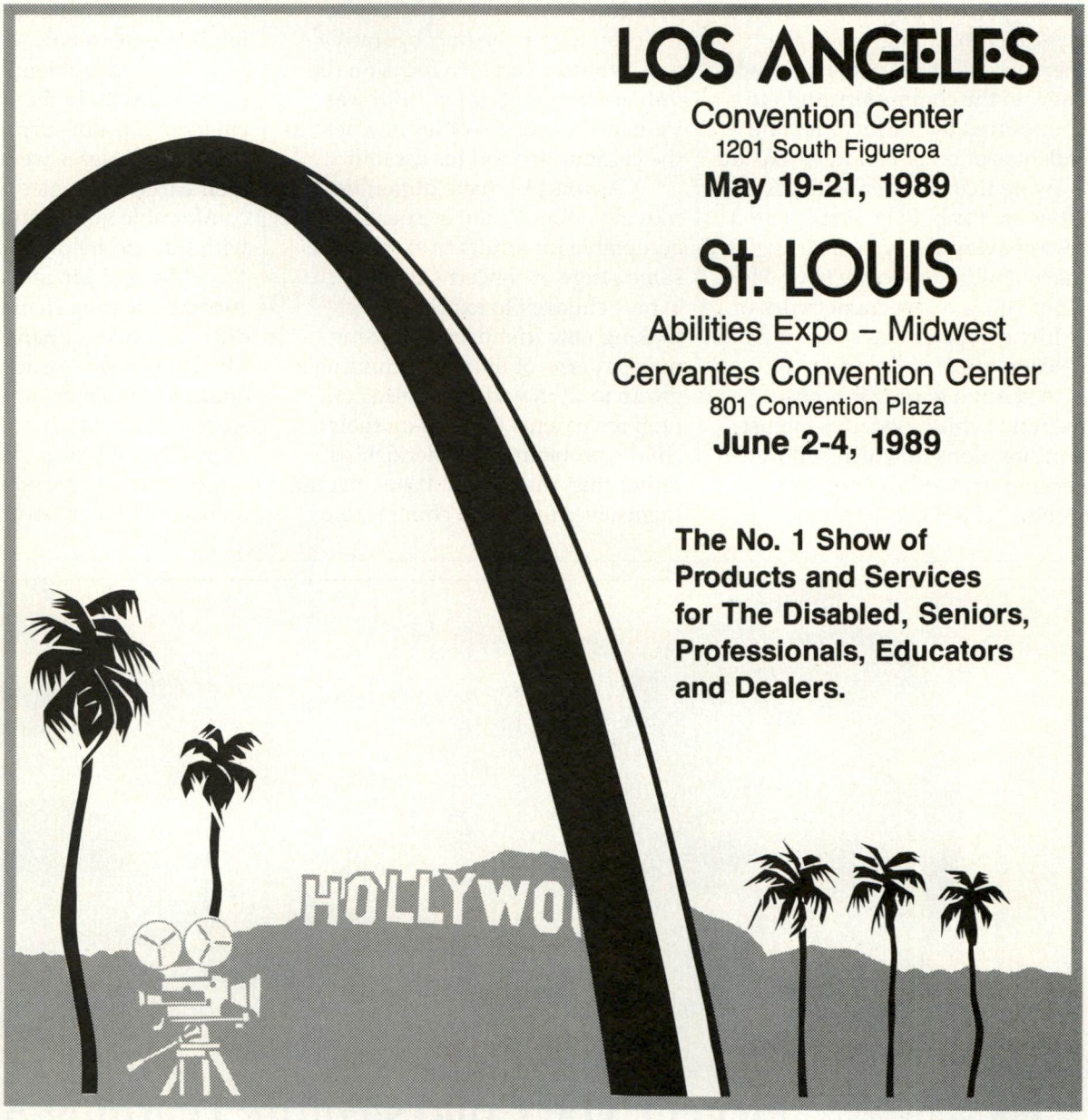

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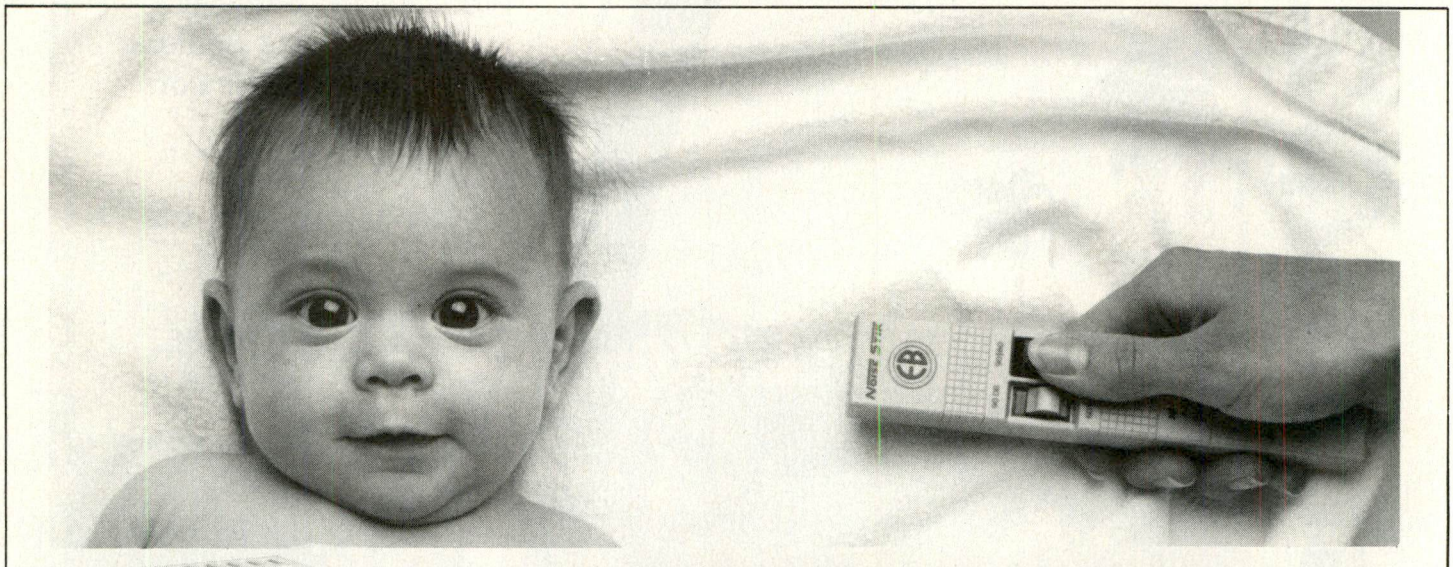
children in a school system are new in any given year. As a result, a greater understanding of the challenges that the new child and family must confront has developed. Teasing and scapegoating are common phenomena for all new children. Children tend to focus on the youngsters in school who are the most vulnerable. In general, the vulnerable children are the ones who are new to the community and are not supported by the loyalties and friendships of other children. We are also aware that children with disabilities are likely to be scapegoated. Bill was having the typical struggles of many children who are new. He had not yet developed a network of new friendships or ways of using his non-school time.

Although teasing is a phenomenon of childhood, it is intensified in situations in which children are encouraged to be competitive. Bill's new school was part of a system that was much more competitive. It placed much more emphasis on high achievement than his previous school system. Youngsters in highly competitive systems often feel continuously vulnerable. They often are fearful that any less than perfect performance will doom them to a life of failure. Under such pressures, children tend to be uncooperative and, when anxious, to focus on the vulnerabilities of others. Bill was vulnerable because of his newness to the community and his disability.

Adults also have difficulties moving . But it's not as socially acceptable for adults to express the same range of concerns that we expect children to express about making new friendships, finding new patterns of living and finding a group to fit in with. It is also common for parents to focus on their child's problems and friendships rather than their own. When parents themselves feel more comfortable and find new networks of relationships, children also settle down.

Mr. and Mrs. Charles agreed that Bill had become a focus of the unresolved disagreements they had about the importance of friendships, the nature of Mr. Charles's career and the supports that each supplied for their son. It is common, when families enter a new stressful situation, for problems that they had struggled with in the past to re-emerge. It is not surprising, then, that the Charleses were reminded of their earlier struggles with finding a comfortable family style for living with Bill and helping him grow.

Much of Mr. and Mrs. Charles current dilemma stemmed from their different styles of handling problems. Mr. Charles was an active man. He attacked problems directly. If there were a dilemma, there had to be an immediate solution. He was much more likely to depend on himself and on his own inner resources for



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solving problems. He had also been concerned about the move. His solution was not to move the family at first and to commute to the new job. On the other hand, he had not recognized the amount of support that his wife had given to him to ease some of the dilemmas of commuting.

Mrs. Charles' style was to turn to her network of friendships for help. Because of the availability of a vast network of friends and relatives in the past, she was able to help her son develop a sense of mastery and acceptability, which eased his negotiations with other children in the neighborhood and at school. When faced with stress in their new community, Mrs. Charles did not have this network available. At the same time, she had underestimated her husband's concern for herself and for Bill.

The Charleses were encouraged to continue to meet during the year and to discuss how they worked together as a husband and wife and as parents. They also agreed that once a month, they would include Bill in their meeting.

The first meeting with Bill gave them a new view of their struggles as a family. Bill was very aware of the differences of opinion between his parents. He felt that if he said postive things about his new school, although he would please his father, he would be siding against his mother. At the same time, he felt that if he discussed his loneliness, he would be criticizing a man who Bill knew cared about him deeply.

The Charleses began to discuss how Mr. Charles' approval was important to his wife and his son. Mr. Charles realized that he already had a large number of people he knew in the community through his new job. Although traditionally Mrs. Charles had been the one who arranged their social life, he felt that he could take a more active role in helping his wife bridge that gap. He began to invite friends from work and their families to their new home. This helped to develop a new network in the community for the entire family.

As Mrs. Charles found herself more comfortable in the community, she found that it was easier to call her old friends and to begin to reestablish a new pattern of relationship with them. As the family felt more involved with each other, Bill found it easier to approach other youngsters. At times he was disappointed, but he gradually was able to establish a new network of friends with whom he could spend afterschool and weekend hours.

—M.J.S.—

This case has been selected from private practice and consultation files. The names and circumstances have been changed to preserve confidentiality.

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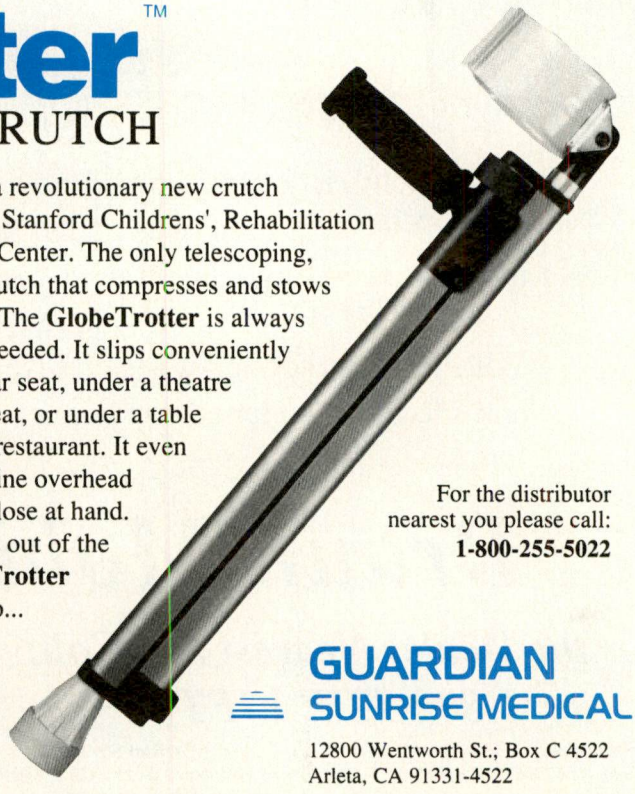

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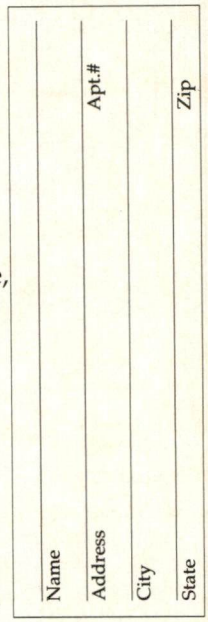

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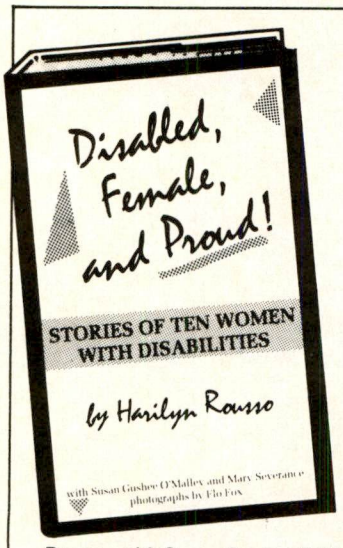

Exceptional Parent Press proudly announces the publication of **Disabled, Female, and Proud!**: *Stories of Ten Women With Disabilities* by Harilyn Rousso with Susan Gushee O'Malley and Mary Severance.

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"You do not have to be or become any one thing because you are a woman or because you have a disability. There are a range of possibilities from which you can choose." *-Harilyn Rousso*

"Don't overstate your disability and don't ignore it. Be assertive. Figure out what you want and don't let people who say you can't get there convince you that you can't do it. Keep fighting, keep using your head, keep finding as many avenues toward where you want to go as you can." *-Adrienne Asch*

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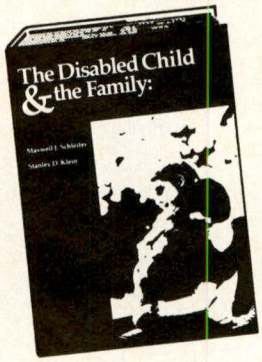

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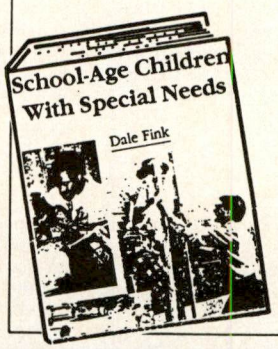
2. describe ways in which computers can be used to make significant impact on people.
3. communicate the possibilities computer technology is opening up for people with disabilities without exaggerating the value of the computer as a miracle cure.



Are children with physical, mental, emotional, medical or other disabilities welcome to attend Extended Day Programs, Latchkey Programs, Kids Clubs, and other school age child care programs which have established across the U.S. in recent years? Or are they and their parents finding themselves shut out of these new initiatives?

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MY FISHING TRIP

By Jason Kingsley

I went on a fishing trip with my Grandpa.

We packed some lunch so we could eat it at the park. We packed my fishing poles, my worms and a bucket.

We went to Gedney Park. We found a pond that has lots of fish.

First we put together the fish-ing pole. We put the string on it. Then we put the float on it and then the hook. Grandpa showed me how to cut the worm and put it on the hook, just by pushing the worm.

Then we stood on the rock and we fished, while my Grandpa took another fishing pole with a reel.

First we cast it out and let the float float on the water and wait until the fish comes. We took 10 fish. They are called sunnies. But there is one fish that we kiss for good luck and throw back in the water. That is the first fish. That is an old family custom.

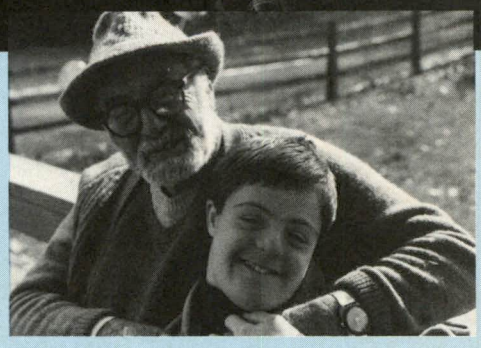
It was great and nifty.

Then we ate some lunch. I ate a tunafish sandwich. I learned how to eat tunafish at camp.

When we got home, my family took a look to see how many fish we got. My family counted the fish one by one and was proud of me.

My Grandfather scraped off the scales of the fish and then cut it with a big knife. He took the faces off and threw them in the garbage. And we eat the bodies for dinner. But for me, I'm having fishsticks from the freezer.

THE END



Jason Kingsley, 14 1/2, is pictured with his grandfather, Alan F. Perl.

Jason lives in Chappaqua, N.Y., and attends the eighth grade at Lakeland-Copper Beech Middle School.

Jason is an aspiring actor who has appeared on the TV shows Sesame Street and The Fall Guy.

STRIDE FOR STRIDE

The clock strikes seven o'clock in the morning. A new day begins with tasks to be done, obstacles to be overcome and feelings to be experienced. As a victim of cerebral palsy, I, Scott Tooke, have lived through many daily experiences. Just as a jockey pursues a career of conditioning to race horses, I have seized the opportunity to achieve academically and socially. The following two questions still persist in my mind as they do in the minds of many other disabled friends: Is the triumph of living worth the risks? Do others assist us in our lives just to acquire that good, warm feeling inside of them?

At the present time, I am a junior at Texas Tech University. My major point of academic interest is in technical writing. I am hoping to land a decent job one day, so that I can support myself and a family. During my high school career, I maintained a 4.2 grade point average to graduate with high honors. The faculty at Coronado High School honored me with the "Who's Who" award in my sophomore and senior years. In order for these achievements to become realities, three communication devices, the Autocom, the Light Talker and the SpeechPac, have played major roles in accomplishing these thrills of victory!

Of course, this fame and honor builds pride deep down within me. However, being this noble, and communicating in a unique way, set the stage for some special, yet normal feelings and emotions. Just as a professional athlete assumes a label as a star, I have been considered the "guy with the neat machine." This has caused a bit of loneliness.

Part of the problem lies in my ability to broaden my communication horizon to include more people. The other part of the problem lies in our naturalistic society. Another common feeling is frustration. Many disabled persons use adapted equipment on a trial-and-error basis. When equipment does not function properly, it places limitations on their abilities. Frustration also comes out when nonverbal persons attempt to show certain kinds of affection to selected individuals. More feelings are experienced when the college students, who are counselors at camp, volunteers at school or in the community or graduate students doing research, leave for jobs to benefit more persons with disabilities. Thinking that these good friends used me as a guinea pig just to obtain their education has been a hard task. I have suffered through times of discontent, loneliness, love, frustration and anger over these people. The following poem suggests more deep feelings about this issue:

To Thy Self

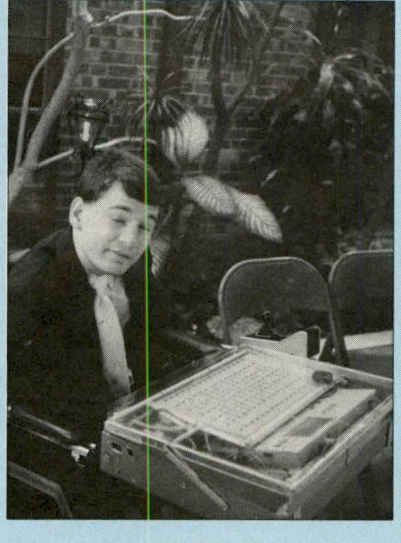
Are you willing to water the flowers?
Do you expect a good fragrance
From doing this deed?
What growth analysis can be anticipated?

Do you promise thy self that these
Flowers will live?
Is there any hope of them living on
Independence?
Would it be a miracle if they lived?

Then, what happens to them when they
Are abandoned?
Do they stop blossoming?
Do the friends even care?

Abandonment is a very severe pain, although my friends are probably still watching every move that I make. The feelings are still here; however, my friends are worth a great deal to me. Every friend in the world is a precious jewel.

Thus, as nonverbal persons live in their fixed environment, they are urged to put out extra effort to broaden their world of communication. A few are keeping up stride for stride, attempting to advance to a more abundant life. Others are reaching out to more people with their unique way of communicating.



Scott D. Tooke, pictured with his SpeechPac communication board, is a student at Texas Tech University in Lubbock, Texas. Tooke is a member of Alpha Phi Omega and is also active in Lubbock Independence for Everyone.

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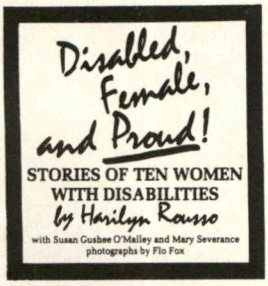

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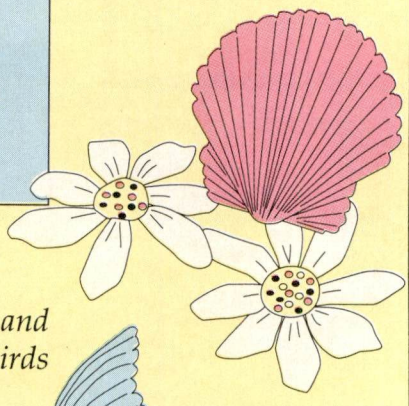
HOBBIES, CRAFTS and GAMES

by D. J. Orr

Some children do not "pick up" new skills as easily as other children. They often need to review and practice skills before the skill is actually learned.

With your child, or your child alone:

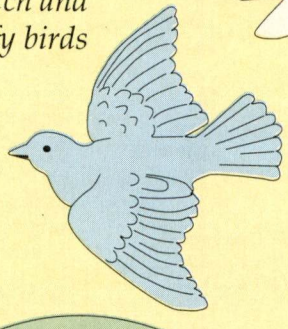
1. Collect flowers, leaves, rocks, coins, stamps, shells, etc. and talk about them.



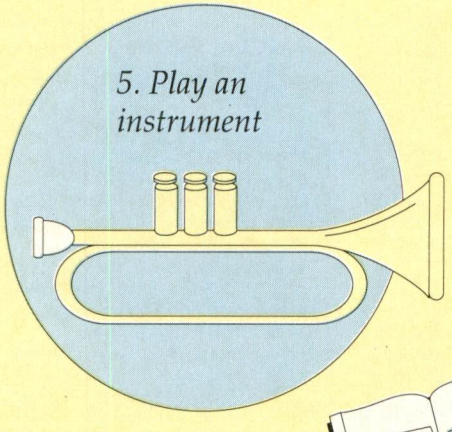
2. Plant an indoor garden

3. Exercise, swim, run, bicycle, hop-scotch, jump rope

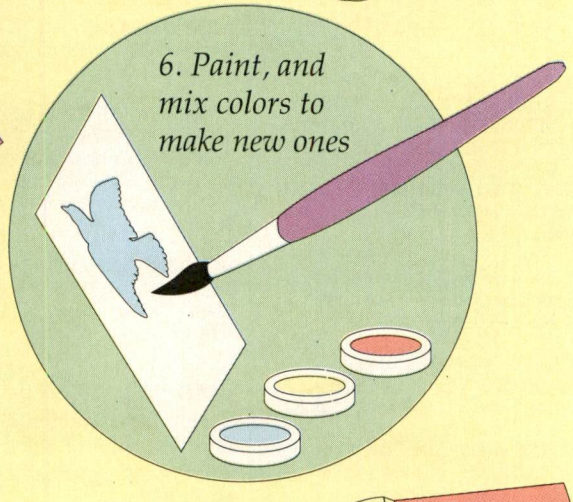
4. Watch and identify birds



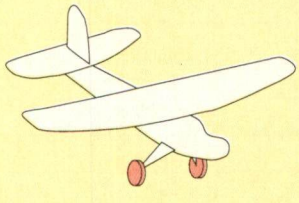
5. Play an instrument

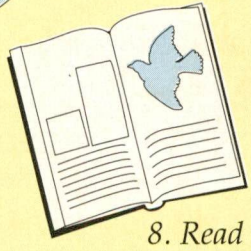


6. Paint, and mix colors to make new ones



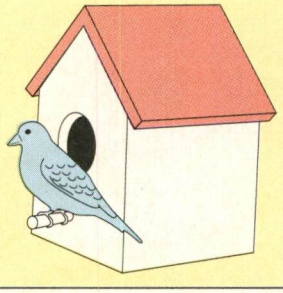
7. Build models

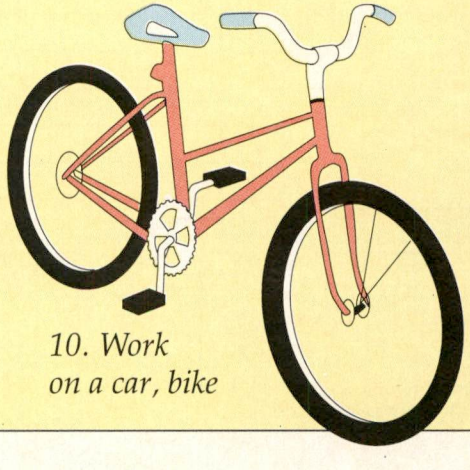




8. Read

9. Build something out of wood





10. Work on a car, bike

11. Make things by sewing, macrame, crocheting, knitting, needlepoint, leather craft, mosaics, decoupage, candlemaking, whittling, sand art, bread sculpture, flower arranging, etc.

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