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ABSTRACT

This report examines day care needs and services for families with handicapped children. A section providing background information identifies barriers to finding day care for these children and discusses the relevance of federal legislation, especially the Americans with Disabilities Act of 1990. The next section presents information on standards for day care, training needs, the importance of collaboration, the role of grants in underwriting training of child care workers, available funds, and employer resource and referral programs. The next section recounts one parent's difficulties in obtaining day care services. Case studies are then presented of model programs including the John F. Kennedy Integrated Developmental Educational and Loving Child Care Center (Denver, Colorado) at which 25 percent of the children have disabilities; International Business Machines which offers financial assistance and a liberal leave policy to employees with disabled children as well as assistance in expansion of a local day care center; the Trident Child Development Center (Charleston, South Carolina), which is associated with a medical center and includes children with special needs; Steelcase Inc. (Grand Rapids, Michigan), which offers a resource and referral service to employees; and Los Angeles Department of Water and Power, which finds child care providers for children of their employees with special needs. (DB)

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Special Report #43

Caring For Children With Special Needs

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INTRODUCTION

...going to work often serves as a much-needed respite for parents of children with severe disabilities.

Finding high-quality, affordable child care—often a difficult task for any working parents—almost always is a nearly impossible chore for parents of children with physical and mental disabilities.

Many parents of children with disabilities, and thus with special needs, have found it so difficult to obtain adequate day care that they forego jobs or work only part-time, so they can stay home and take care of such children, according to Suzanne Ripley, deputy director of the National Information Center for Children and Youth with Disabilities (NICHCY). This reduces the income of the very families that need additional funds for the extra needs of a child with a disability, Ripley told BNA.

Moreover, lack of full-time employment and children's disabilities that most health plans treat as uncovered pre-existing conditions make adequate health insurance costly and difficult or impossible to obtain, exacerbating the problems of families that have children with disabilities, she added.

In addition, experts point out that quality-of-care considerations that confront all parents seeking child care—safety, staff training, children-to-teacher ratios, costs, and location—are even more important for parents of children with special needs. For example, a low children/teacher ratio is more important for children who use wheelchairs and may need help eating, dressing, and going to the bathroom, than it is for children who are able to perform these activities without assistance.

Anecdotal evidence and experts interviewed for this special report suggest that any help employers can provide to employees' children with special needs will reduce absenteeism and turnover, increase productivity, and improve the care of all workers' children.

Carolyn Nava, co-founder of Golden Buckets, a Denver, Colo., foster care program for children with special needs, said going to work often serves as a much-needed respite for parents of children with severe disabilities.

For example, Nava said she became extremely distressed after just one weekend of taking care of a child with cri-du-chat syndrome, a chromosome disorder that caused the child to cry almost constantly. Afterward, she wondered how the child's parents were able to cope with the situation over long periods without a break.

Companies benefit from having such employees because they often look forward to going to their jobs, and many of them are excellent workers whose jobs enable them to stay "connected" to social activities and other adults their age, Nava told BNA.

However, where day care for such children is not available, at least one of their parents cannot hold a job, and everyone loses. Employers lose a potential employee-parent who may be highly qualified and almost surely is highly motivated, while the worker-parent that does hold a job is beset by problems related to child care that meets special needs.

In addition, a 1984 U.S. Census Bureau study found that "children with disabilities were more likely to live in female-headed, single-parent households that receive a higher percentage of their income from government programs." Moreover, studies by David Salkever, professor of health economics at Johns Hopkins University Medical Institutions, cited in the Summer 1988 issue of *Maryland Child Care*, the Maryland Committee for Children Inc. newsletter, concluded that "mothers of disabled children work an average of 100 hours less per year than their counterparts with no disabled children. The earnings of these mothers are estimated to be 20 percent lower than average as a result of children's disabilities."

Providing child care that includes meeting the special needs of children with disabilities can enable many of these parents to work and get relief from having to provide 'round-the-clock care, while reducing the financial burden on government, experts note.

Many of them also maintain that without early intervention that includes child care, the families of children with disabilities are more likely than others to experience above-average rates of stress-related family difficulties like spouse abuse, child abuse, and divorce.

The divorce rate among parents of children with disabilities probably is higher than the national average because such children "have a broad range of impact on everything you do, every day," and as a result "marriages undergo stress," says Claudia Segal, referral counselor for the special needs program of the Child Care Connection, a resource and referral service in Montgomery County, Md.

"If families don't get help early" for children with special needs "you will have a disabled family," Fred Weintraub, assistant executive director of communications for the Council for Exceptional Children, said.

"Dysfunctional children make parents dysfunctional," Golden Buckets' Nava said.

Providing parents with respites from taking care of children with disabilities reduces the child abuse that sometimes occurs when parents become

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overburdened with trying to meet children's special mental and physical needs, she added.

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BACKGROUND

About 300,000 children under age 5 have a physical or mental disability, according to the U.S. Census Bureau, and experts say the figure probably is higher because many disabilities are not diagnosed until children reach school age.

Charlotte Thompson, a pedi rician and director of the Center for Handicapped Children and Teenagers in San Francisco, estimates that 6 percent of all children up to age 5 and 12 percent of all school-age children have disabilities.

Data is not available on how many preschool children with disabilities are from homes where both parents work or want to work but cannot because day care that includes meeting children's special needs is not available. Data also is lacking on the number of children with disabilities who receive child care, including employer-provided care or care obtained through companies' information-and-referral programs.

Some Denied Care

Many child care providers, including employer-supported facilities, do not accept children with disabilities. Although no national figures on this problem are available, some state and local data has been compiled.

The Maryland Committee for Children Inc., which operates LOCATE: Childcare, a statewide computerized resource and referral service, regularly surveys child care providers to determine if they accept children with disabilities.

Only 1,881 of 10,293 family day care providers surveyed in January 1991 said they would accept children with special needs; another 1,092 said they would "consider" accepting such children, but would want to talk first with the parents and obtain more information on a case-by-case basis.

About 300,000 children under age 5 have a physical or mental disability, according to the U.S. Census Bureau...

...from July 1990 through June 1991 the organization received 228 calls from parents of 237 children with special needs seeking child care.

Only 300 of the 987 child care centers surveyed said they would accept children with special needs; another 145 said they would consider accepting them, according to Arna Griffith, LOCATE: Childcare director. Griffith told BNA that from July 1990 through June 1991 the organization received 228 calls from parents of 237 children with special needs seeking child care. The committee was able to find adequate care for many but not all such children, according to Griffith.

Stanley Kuziel, vice president for marketing of The Partnership Group Inc., a national child and elder care resource and referral consulting service in Lansdale, Pa., said only eight to 13 of 250 child care providers in the firm's Philadelphia-area database offer specialized care and facilities for children with disabilities. Another 25 are equipped to accept children with special needs, and about 125 would "consider" accepting children with special needs. Of the 250 providers, about 187 accept children from infancy through preschool; most of the other 63 or so limit admission to toddlers and preschoolers. Ten of the providers are employer-sponsored centers, all of which said they would consider accepting children with special needs. Eight of the 10 are hospitals.

A 1988 Berkeley Planning Associates survey for the California Department of Education estimated that 159,000 children with disabilities in the state have working parents. About 25 percent of these children were age 5 or younger. The study concluded that "at least 80,000 of the employed mothers" of children with disabilities needed child care.

About 84 percent of the survey respondents used some type of ch" ' care, "much of it informal and/or unlicensed. Two-thirds of all child care used by these families was located in homes, either their own or that of a family day care provider, friend, or relative," the survey noted.

The study found that only two "state-supported child care programs ... specifically target children with disabilities: a Program for Severely Handicapped Children in six sites, serving children with severe disabilities in segregated, specialized settings; and a Mainstreaming Program in ten sites, providing child care and development services to exceptional needs children in integrated child care settings."

The two programs serve a total of only 300 children. Less than 1 percent of enrollment of other "state-subsidized programs" that are allowed to bill at a higher rate for children with disabilities did so, suggesting strongly that they had no such children enrolled.

"The current level of direct state support covers fewer than 1,000 of the exceptional needs children requiring child care services," the study concluded.

It also found the following barriers to finding day care for children with disabilities:

- Lack of alternatives—parents had to settle for whatever arrangement they could find and did not have enough options.
- High costs—"Problems with the cost of child care were not limited to low-income families—the expense of raising a child with disabilities puts many middle class families into the category of the working poor. One employed professional parent estimated spending $10,000 a year on child care for one child. Many mothers described promising careers or higher-paying jobs that were lost due to inadequate child care."
- Need for training child care providers—"Among a list of possible reasons for a provider's refusal to accept their child, parents most frequently reported 'caregiver has no prior experience with disabilities or exceptional needs.' "
- Need for appropriate program design—Parents and providers expressed a keen interest in mainstreaming children with disabilities. Many noted a "gap in child care services for school-age children" with disabilities, especially after-school care programs.

Elinor Guggenheimer, founder and president of the Child Care Action Campaign, headquartered in New York, argues that businesses "have an obligation to society" to use their influence to change national policy on child care for children with special needs. Guggenheimer told BNA that "business can never solve the problems" and solutions must come from "national policy as it does in every other country. Business can convince government it needs a policy for children of all kinds." The problems of children with special needs have been thoroughly studied and "we know exactly what to do, we just don't do it," Guggenheimer said.

"Business can convince government it needs a policy for children of all kinds."

Federal Laws

Although the federal government currently does not set national standards for child care, several federal laws affect child care providers:

- Improving day care for children with special needs, including training for teachers and aides, is a listed goal for over $700 million in new block grants to the states under the child care provisions of the Omnibus Budget Reconciliation Act of 1990.
- Nursery schools and day care centers are among the facilities listed in Title III of the Americans with Disabilities Act of 1990 (ADA), which, starting Jan. 26, 1992, prohibits discrimination in public accommodations and services operated by private entities.

The law bans discrimination against people with mental and physical disabilities in admissions or eligibility criteria, including those for child care; requires that facilities be modified to make them accessible; and requires "auxiliary aids and services" necessary to ensure that "no individual with a disability is excluded, denied services, segregated or otherwise treated differently than other individuals."

ADA also requires the removal of architectural and communication barriers from facilities...

ADA also requires the removal of architectural and communication barriers from facilities, and if removal is not "readily achievable," requires that "alternative methods" be used to make the delivery of "such goods, services, facilities, privileges, advantages, or accommodations" possible.

Although these provisions apply to child care providers, observers say ADA's "readily achievable" and "undue financial hardship" qualifying language would enable many small child-care centers and in-home day care providers to avoid having to comply.

The Child Care Law Center, in San Francisco, noted in its winter 1990 *Legal Update*, for example, that under ADA "a program serving a blind child might need to purchase some Braille books or audio tapes of well-known children's stories." However, the publication also emphasized that:

> Since the "undue burden," "undue hardship," and "readily achievable" standards ... take into account the size and budget of a business in determining compliance with various provisions of the ADA, it is likely a struggling small business will be excused from compliance where a larger, more prosperous business will be required to comply. Family day care homes are not specifically listed in the ADA public accommodation provisions, and it appears that the small business nature of a family day care home would exempt providers from compliance with some provisions of the ADA.

Despite these limitations, Kathleen O'Brien, a staff attorney with the Child Care Law Center, predicted that ADA will spawn a sharp increase in telephone calls to the center from providers and parents.

Child care providers that receive federal funds also are covered by Section 504 of the Rehabilitation Act of 1973, which prohibits discrimination by most federal grantees and contractors against people with disabilities, experts point out. For example, many providers are reimbursed some of the costs for food that is served to children in their care through the Child and Adult Care Food Program administered by the Department of Agriculture's Food and Nutrition Service.

The Education for All Handicapped Children Act of 1975 guaranteed to all children with disabilities from ages 3 through 21 the right to a free and appropriate public education. Although the act required state and local education agencies, as a condition of receiving federal grants, to develop individualized education programs (IEPs) for children with disabilities ages 6 through 17, it only recommended that the same rights be applied to children from ages 3 through 5.

Under the Individuals with Disabilities Education Act of 1986, children ages 3 through 5 whose parents are unable to provide day care are entitled to a free appropriate education through a preschool program like Head Start. Although the act requires states to develop, by September 1991, individual family service plans that ensure that the medical and educational needs of children with disabilities are being met, Fred Weintraub, of the Council for Exceptional Children, said Congress probably will extend the deadline.

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STANDARDS, TRAINING, AND AID

No federal laws set standards for child care providers, including those who take care of children with special needs. Most states set their own standards with regard to licensing child care providers, and few of them have special requirements for taking care of children with disabilities.

The 40,000 providers who have received CDA credentials represent a "very small percentage of the millions" of providers and only a "very small percentage" of the 40,000 provide day care for children with disabilities...

The National Association for Education of Young Children's Council for Early Childhood operates a national Child Development Associate (CDA) credentialing program for child care providers, but it has no special standards for those who take care of children with disabilities. The 40,000 providers who have received CDA credentials represent a "very small percentage of the millions" of providers and only a "very small percentage" of the 40,000 provide day care for children with disabilities, according to Deborah Jordan, program coordinator.

The association probably will add credentialing for providers who take care of children with disabilities within the "next couple of years," Jordan told BNA. The organization is receiving "more and more calls" about caring for children with special needs, she said.

Although CDA credentials and other licensing requirements are "very good," they are "no guarantee" of quality day care because "not enough licensing inspectors" exist to make sure the requirements are met, Stevanne Auerbach, author of Keys to Choosing Child Care and other books on the subject. told BNA. The standards vary widely among states, she added.

Although most states set child/teacher ratios, they differ widely among the states. A low child/teacher ratio makes it easier for providers to take care of children with special needs, especially those with severe disabilities. Massachusetts and California have the highest child care provider licensing standards, according to Barbara Burns, vice president for education for Bright Horizons Children's Centers, a network of 39 child care centers, including several employer-supported facilities.

Training

A "vast gulf" sometimes exists between having laws designed to ensure that children with disabilities have access to child care and "someone watching my baby, and me trusting them to take care of [him or her]," noted Suzanne Ripley, of the National Information Center for Children and Youth with Disabilities (NICHCY).

Improved training for staff is one way to achieve an adequate level of trust and "training is going to be one of the ongoing issues" for providers who accept children with disabilities, Burns said.

The goal of training teachers and aides to take care of children with special needs should be to "fit the program to the child and the family we serve, not fit the child to the program. Every child is an individual," she added.

Collaborative Effort Stressed

Providers who care for children with special needs should strive to create partnerships that include themselves and their staffs, the children's parents, and outside specialists, including educators and medical personnel.

Providers must use a "team concept," according to Karen Leibold, director of work and family programs for the Stride Rite Corp., a leading manufacturer of children's shoes, headquartered in Cambridge, Mass. Stride Rite operates two child care centers, each serving 55 children. Both centers have enrolled children with special needs. Leibold said creation of such partnerships that include parents and public school officials is the "biggest transition" facing child care centers as they start serving children with special needs. It is "somewhat difficult for the team to be expanded" and a level of trust to be established among parties who previously did not have to deal with each other, she said. Public and private resource and referral agencies that include programs for children with special needs can help facilitate these transitions, Leibold added.

The goal of training teachers and aides to take care of children with special needs should be to "fit the program to the child and the family we serve, not fit the child to the program."

Questions Urged

Experts stress that child care staff members being trained to provide for children's special needs should not be afraid to ask questions if they do not understand something about a particular disability.

Ripley advised providers who decide to accept children with special needs not to be "scared. Feel free to ask questions." Trainees who have been taught from the time they were children "never to stare at" or ask questions about people's disabilities, must acknowledge that they have no "prior experience with a disability. The rest falls into place," she said. Ripley, who has a child with a disability, said other people probably will not observe anything about children with disabilities that their parents have not already noticed.

When one of Stride Rite's two child care centers accepted a child who suffers from seizures, the child's pediatrician came to the center and showed the staff how to assist her if she had a seizure while she was there.

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Some state nurse-practice laws prohibit such training, experts advise. For example, in Colorado nurses may teach parents, but not other care providers, how to perform certain medical procedures, according to Nava, of Golden Buckets. Because of this, the parents of children with disabilities—not nurses—must teach child care providers how to meet their children's special needs, she explained.

Grants Underwrite Training

Training is "one of the most important" components of providing quality day care for children with disabilities, according to Susan Craig, coordinator of a project called the Successful Integration of Infants and Toddler with Handicaps Through Multi-Disciplinary Training. Funded by a U.S. Department of Education grant, the project provides 15 hours of training for child care providers who take care of children with disabilities.

The training focuses on physical environment; safety; promoting health and nutrition; physical development; cognitive development; communication; social development; positive guidance; working with families; and preventing child abuse.

Craig, a consultant with AGH Associates, a Hampton, N.H., consulting firm specializing in the education of children, has established these four model programs:

- An on-site infant/toddler child care center at the U.S. Army's Fort Meade in Maryland;
- Family child care homes at the Army's Aberdeen Proving Grounds, also in Maryland;

- A small community-based, private child care center for toddlers in Reading, Mass.; and
- A large community-based private center in Manchester, N.H., that accepts children ages 6 weeks through 12 years.

The on-site training includes such topics as basic infant nutrition and oral motor skills. The training is designed to "prepare a center to accept" children with special needs, Craig said.

Administrators' Evaluations Needed

Child care center administrators who plan to admit childrer with disabilities should examine policies and procedures, including enrollment forms and parent handbooks, from the perspective of "how would this work for all children," Craig said. "Children are more similar than different." The federally funded project provides more comprehensive training for directors and assistant directors of child care centers, and for administrators who determine child care centers' environments.

In addition, Craig includes "everyone at a site—from the janitor to the administrator"—in a session called "The Philosophy of Inclusion of Children with Disabilities," which emphasizes that "children share more similarities than differences, regardless of ability." "It's important for all children to have a childhood where they can develop social relationships," she said. Craig believes that because "day care helps all parents acclimate to parenthood," it is "important for all parents to have access to" that experience.

"It's important for all children to have a childhood where they can develop social relationships."

Special training like that provided by the project reduces the stress on child care staff members and makes them more willing and able to care for children with disabilities, she said, adding that staff training for special needs improves the quality of day care for all children.

Funds Available

The special needs project of Resources for Child Caring, a St. Paul, Minn., a child care organization that includes a resource and referral service, has provided child care staff training on caring for children with disabilities, under grants from Ramsey County, Minn., the state Department of Education, as well as private donations. The training is designed to make child care more readily available to parents of children with disabilities, according to Sherry Haaf, program coordinator.

"Training and education also are provided through classes on children with special needs as well as individual consultation with child care centers and family day care providers," Haaf said. "One of the things that we're also able to do is provide substitute dollars so that child care providers can attend meetings regarding children with special needs. For example, the dollars can be used for individual education plan meetings, meeting with medical personnel, or observing a child in a school setting," she added.

"One of the things that we're also able to do is provide substitute dollars so that child care providers can attend meetings regarding children with special needs."

The grants also have been used to buy a "limited amount of adapti equipment"—including items designed to improve balance and walking, to assist children who lack well-developed motor skills; and special equipment to help blind children—that is then lent to child care providers.

Haaf and her staff also work with schools, parents, and child care providers to structure programs for children with special needs. Haaf insists that participants in these efforts discuss candidly the child's disability and what they think the program can achieve. She also recommends that the same parties meet after a few weeks to assess progress.

Resources for Child Caring has developed a letter that poses several questions which the provider and the parents of a child with disabilities should consider before the child is enrolled in the provider's day care program. Haaf believes that day care of children with disabilities has a better chance of success when a maximum amount of information is exchanged before the child is enrolled.

For providers, the letter asks:

- How do you feel about people with disabilities? A child with a special need is a child first and disabled secondly.
- What is your child care daily schedule? Do you have a structured scheduled or is your program unstructured? Are there many transitions throughout the day?
- What is the adult/child ratio?
- What is your philosophy of caregiving? Is it child-centered, focusing on socialization/peer interaction, or academic? and
- What are your expectations for all children, including the child with a special need?

For parents of children with disabilities, the letter asks:

- How does your child communicate needs?
- What are your child's motor abilities?

- What are your child's self-help skills (especially eating, toileting, dressing)?
- Describe medications; what they are used for and who is responsible for dispensing them? and
- Describe other medical needs of your child.

Data on Resources Provided

The National Information Center for Children and Youth with Disabilities uses Department of Education grants to distribute fact sheets on organizations in each state that assist children with disabilities. The center also operates as a nationwide clearinghouse of information on children and youth with disabilities. The clearinghouse distributes free information on a wide variety of topics of interest to providers and parents of children with disabilities through toll-free telephone inquiries and written requests. Telephone: 1 (800) 999-5599; or (703) 893-6061 in the Washington, D.C., area; and (703) 893-8614 (TDD). Address: National Information Center for Children and Youth with Disabilities, P.O. Box 1492, Washington, D.C. 20013.

Resource and Referral Programs

"Most families face difficulties placing a child with special needs in child care," said Claudia Segal, the referral counselor for the special needs program at the Child Care Connection (CCC) in Montgomery County, Md. Parents face a lack of public understanding about the extra attention children with disabilities require, Segal told BNA.

Segal's job was established in 1987 because parents of children with disabilities were looking for providers with skills not indicated in the agency's general referral list.

Members of CCC's special needs child care referral program staff conduct detailed interviews with parents and health care and educational professionals who are familiar with the child to determine the child's skills, Segal said. The interviews also provide the program staff information about the child's developmental and medical problems and about medicine the child is taking.

"The intensity and detail of our intake make a difference," Segal said. "It enables us to call the provider with a real idea of what the child is like." Participating providers complete questionnaires that indicate their interest or experience in taking care of children with disabilities. In 1990, the program gave 152 families referrals for child care for children with disabilities, including mental retardation and learning disabilities, orthopedic handicaps, and speech, vision, and hearing impairments. After the intake is completed,

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the staff sends parents a list of providers who are interested in caring for children with disabilities, plus a computerized listing of all child care providers near their home or jobs.

CCC provides additional services related to caring for children with special needs. For example, the organization helped a working mother receive an unpaid maternity leave extension by explaining to the woman's employer that her baby with a breathing disorder was connected at home to a machine that monitored the infant's breathing. "Parents of children with these types of problems may end up losing their jobs" unless employers take steps to meet their special needs, Segal noted.

Resource and Referral Preferred

Statistics show that more employers sponsor child care resource and referral programs than subsidize direct child care programs, and the number of privately and publicly funded organizations that help families find child care is growing.

The National Association of Child Care Resource and Referral Agencies has over 400 member agencies, according to Tutti Sherlock, association director.

Resource and referral services obtain information from parents that includes how much they can afford to pay, the preferred location for the child care, and, in the case of children with disabilities, pertinent medical information.

Pat Ward, who started the in-house resource and referral service at Steelcase, Inc., a Grand Rapids, Mich., office furniture manufacturer, said many employers can provide "a higher level of resource and referral" for employees whose children have disabilities because companies often employ people who have better "training and expertise" relating to special needs. "Sometimes, community-based resource and referral programs have used entry-level" people to conduct intake, said Ward, who is director of the family day care program at the National Council of Jewish Women, although she added that community-based services are improving.

Some employers try to make sure that employees who have small children with disabilities know that the company's resource and referral service may be able help them.

For example, at Baxter Healthcare Corp., a manufacturer and distributor of health products with 38,000 employees, the employee assistance program case manager and the insurance claims case manager and their staffs remind employees who have children with disabilities about the company's resource and referral service, according to Alice Campbell, director of work and family programs at the firm.

Other Employer Aids

Although employer assistance in finding child care is of particular importance to employees with children who have disabilities, most experts say that allowing such employees flexibility in their work schedules also is critically important.

Ward said employers should adopt policies that allow parents to take care of children with disabilities as much as possible. For example, she cited the case of one of the children in the care of her sister, a child care provider. Because the child has cancer and receives chemotherapy on a regular basis, the mother's employer allows her to work a flexible schedule that enables her to take the child for treatment.

Dale Borman Fink, research associate at Wellesley College's Center for Research on Women and author of *School-Age Children with Special Needs: What Do They Do When School Is Out?*, said "Many parents whose children have special needs don't even bother seeking employment because they need an employer who understands that they will take time off when they have a child in need of surgery or who has other complications.

"Employers are missing out on a lot of very talented people because too few show this degree of flexibility. While it is very important for day care centers and school-age centers to access the resources they need for the inclusion of children with various disabilities, that alone will not guarantee that these families can enter the workforce and pursue their aspirations as do other employed parents. In America today, they will also need employers who can be flexible," Fink told BNA.

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"Employers are missing out on a lot of very talented people because too few show this degree of flexibility."

A PARENT'S PERSPECTIVE

The five-center child care chain where their older daughter was enrolled told them it could not accept Katrina because it would not be able to "carry a two-year-old."

Assertions by day care providers that they will "consider" accepting children with disabilities often ultimately result in negative final decisions and disappointment for such children's parents.

This was the experience of Miriam Simons and David O'Brien, computer programmers who work for different companies in St. Paul, Minn., whose daughter Katrina has cerebral palsy.

In 1987, already the working parents of Anneliese, a two-year old daughter in day care, the St. Paul, Minn., couple had twin girls, born about six-weeks prematurely.

Greta, although small for her age, suffered no permanent diagnosable disability as a result of her premature birth. However, Katrina, who had been prone to systemic infections, had suffered a collapsed lung, and had respiratory problems, was diagnosed as having cerebral palsy when she was about nine months old.

Because of complications surrounding the twins' birth, Simons took eight weeks of paid short-term medical disability leave and three months of unpaid maternity leave, while O'Brien took six weeks of unpaid paternity leave, during which he lost employer-provided life and health insurance. Private coverage for the six weeks was expensive and difficult to obtain, Simons said, adding that her husband also suffered setbacks in his vacation benefits, retirement date, and pension plan as a result of taking paternity leave.

For the first 18 months after Simons and O'Brien returned to work, they hired a woman who took care of the twins in their home.

When the twins were 2 years old, Simons and O'Brien began to seek day care for them outside of the home. Katrina was still unable to crawl or sit up by herself. The five-center child care chain where their older daughter was enrolled told them it could not accept Katrina because it would not be able to "carry a two-year-old."

Simons told BNA that the search for a provider that would accept Katrina became increasingly frustrating, with rejections including statements like: "Gee, I'd love to, but I just can't"; "We would like to take a child like that if she could fit into our program' nd "Our program is not set up to admit a child like that."

Simons said she did not enroll Katrina with any of the few providers who said they would accept her on a trial basis, because she felt none of them intended to enroll her after the trial period. One center refused to accept Katrina because the building where it was located had no elevator and Katrina would have had to be carried up and down several flights of stairs each day.

Trial Placement

After many fruitless inquiries stretching over several months, in August 1989 Simons and O'Brien were able to place Katrina on a trial basis in a center with 100 children, located in the basement of a three-story building that previously was a church-operated elementary school. They also enrolled Greta in the center. The parents provided their own stroller and special adaptive seating. Simons and O'Brien were charged the regular full-time fee for Katrina despite the fact she attended only from 7:30 a.m. until noon each day, when she was picked up at the center and taken by bus to obtain physical therapy from both a private and a public therapist.

Everything seemed to be going fine, Simons said. The only specific complaint that she had received was that Katrina was having trouble napping. Simons later discovered that when Katrina did not go to sleep, the center staff put her crib in the corner of a bathroom. Simons said this probably exacerbated the problem because the stark surroundings of the bathroom frightened Katrina. Overall, Simons said, the reports she received from the center were positive, and when she asked if anything was needed, she was told that "everything is super."

In early October 1989, the center director told Simons: "We're having a lot of trouble with Katrina.

In early October 1989, the center director told Simons: "We're having a lot of trouble with Katrina. All five toddler staff members are having trouble." At Simons' suggestion, the director, Simons and O'Brien, Katrina's physical therapist, and the five toddler teachers met. Two of the teachers said they had no problem with Katrina; two said Katrina, who had to be carried up or down one flight of stairs when leaving or entering the center, was too heavy to carry; and the fifth said the special car seat that Katrina needed to ride on the bus was too ugly, too heavy to carry, and took up too much space.

Simons' suggestion that she make a skirt for the sign-in table at the top of the stairs so the car seat could be placed under the table and out of sight appeared to please everyone. Staff members said they could carry Katrina if they did not also have to carry the car seat.

Katrina's physical therapist pointed out to center officials that because almost all of the children were not toilet-trained, the staff frequently had to

...Simons received a telephone call from the director, who said "my five staff members are threatening to quit" because of Katrina, and told Simons she had two weeks to make other child care arrangements.

lift them to change their diapers, and therefore carrying Katrina, who was the size and weight of an average 1-year-old child, should not be difficult.

Situation Called 'Great'

Two days after an early November 1989 conference on their older daughter, at which Simons and O'Brien were again told that everything was going "great" with Katrina, Simons received a telephone call from the director, who said "my five staff members are threatening to quit" because of Katrina, and told Simons she had two weeks to make other child care arrangements. "It was the worst experience in my life," Simons told BNA.

After exploring other options, including a woman with a one-year-old child with Down's syndrome who said she would take care of Katrina, Simons and O'Brien elected to place Katrina and Greta with a former teacher at the center who had operated a child care service for nine years previously and had left the center to do so again, in her home. The teacher was one the two center staff members who had said she had no difficulty taking care of Katrina.

The teacher said at first it was "very scary" when Katrina came to her home, but she soon realized that she had nothing to fear. Katrina was able to use her walker, and in "no way" has caring for Katrina been "too hard," she told BNA.

The main difference has been that a therapist from the elementary school in Katrina's district, which has a special needs program, visits the teacher's home four times a year, and a private therapist comes to the home once or twice a week.

Although Minnesota child care provider licensing laws, like those in many other states, do not require any additional training to care for children with special needs, Katrina's teacher, on her own time and at her own expense, has taken classes from the Special Needs Project at Resources for Child Caring in St. Paul and from the Wilder Foundation Network. She receives college credit for classes provided by Resources for Child Caring, and she said the organization's information, including seminars and printed material, have been most helpful.

The teacher said she offers no special explanation regarding Katrina to parents of other children in her program or to those seeking to place their children with her, other than to say: "This is Katrina, she has cerebral palsy." No one complained and "most people seemed happy their children were exposed to" a child with a disability, the teacher told BNA, adding that she is enrolling an eight-year-old child with Down's syndrome.

As a result of the fact that Simons now works only part time and her hus-

band works a compressed work week the twins attend the in-home day care facility only one day a week.

Employer Not Supportive

Simons said her employer was less supportive of her decision to work part time than her husband's employer was of his request for a compressed work week. Her company denied her request for a 30-hour work week and approved only a shorter schedule because 30 hours would have entitled her to benefits, she said.

Simons explained that she and O'Brien decided to work part-time primarily so they could give Katrina the additional physical therapy her physician recommended. They are satisfied with the quality and cost of the twins' child care, she added.

Because Simons works less than 30 hours a week, she is ineligible to purchase long-term-disability insurance through her employer, a benefit she said would be essential for the care of her children—especially Katrina's special equipment and therapy—if something were to happen to her.

O'Brien works 40 hours a week, compressed into three 12-hour days at his office plus four hours at home. He receives all employer-provided benefits, including health insurance that covers the entire family.

Simons urged employers to provide subsidies or grants to child care providers to cover any extra costs associated with accepting employees' children with disabilities. She said the employer-paid $25 child care resource and referral service fee was of little value because she and her husband had to do most of the work involved with finding suitable care for Katrina. Simons acknowledged that she has never tried to use her company's sick-child care benefit because she thinks Katrina would not qualify, although she never asked. If neither Simons nor O'Brien is able to stay home with Katrina when she is ill, they hire a nursing service that sends a health care provider to their home. Simons does not tell the nursing service in advance that Katrina has a disability. She explains the situation in a "matter-of-fact" way when the nurse arrives. This has created no problems, she said. Simons added that "it was helpful" when a nurse told her she was apprehensive about performing some procedure with Katrina because she was "afraid she was hurting her." The nurse's candor enabled Simons to explain that she was not hurting her.

Her company denied her request for a 30-hour work week and approved only a shorter schedule because 30 hours would have entitled her to benefits, she said.

She also urged employers to allow parents who have children with disabilities to work part-time schedules that allow them to retain some company benefits, on a pro-rated basis, if necessary.

More mainstreaming of children with disabilities into regular day care settings would reduce the unfounded fears and misunderstandings many children, providers, and parents have about children with special needs, Simons said.

She also urged employers to allow parents who have children with disabilities to work part-time schedules that allow them to retain some company benefits, on a pro-rated basis, if necessary.

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CASE STUDIES

JFK I.D.E.A.L. CHILD CARE CENTER

An enrollment where one of every four children has a disability is a goal of the John F. Kennedy Integrated Developmental Educational and Loving Child Care Center (JFK I.D.E.A.L.) at the University of Colorado Health Sciences Center, located in Denver, Colo.

Begun in 1990, the center is being financed in part by a three-year U.S. Department of Education grant to teach child care providers how to meet the special needs of "medically fragile infants and toddlers," including children dependent on technology for their daily living and those with chronic health needs, developmental delays, and emotional problems, according to Sandra Peterson, center director.

To help achieve its goal, the center maintains a 3:1 child/teacher ratio for infants and 5:1 for toddlers. Although "almost all" of the infants are "typically developed," about 25 percent of the toddlers have disabilities that include breathing difficulties that require the use of a respirator to breathe, cerebral palsy, congenital viral infection, and experiencing "pervasive delays," Peterson said. One child is not growing or developing properly due to a genetic disorder.

To help achieve its goal of having 25 percent of the total enrollment comprise children with disabilities, the center accepts children with special needs from the community.

In addition to receiving direction from Peterson, who is a candidate for a doctorate in early childhood special education, the center staff consults with an occupational therapist, a speech therapist, a nurse, and a psychologist, who are on the staff of the JFK Developmental Center, a university-affiliated program serving people with developmental disabilities.

Admission of children without disabilities is limited to children of university faculty, students, and staff. To help achieve its goal of having 25 percent of the total enrollment comprise children with disabilities, the center accepts children with special needs from the community. Tuition is $130 a week for infants and $92 for toddlers.

University Support

The university pays for the space and maintenance, including utilities and housekeeping costs. Food and para-professional staff salaries are paid from the center's budget. The university contracts with Child Care Partners/High-

If the university employed them directly, they would be part of the state personnel system and would be entitled to salaries and benefits—"so high, that parents wouldn't be able to pay a fee that would support" them, Peterson said.

land Learning Centers, an organization which administers child care programs, to furnish the para-professional staff for the center. If the university employed them directly, they would be part of the state personnel system and would be entitled to salaries and benefits—"so high, that parents wouldn't be able to pay a fee that would support" them, Peterson said.

She said the admissions procedure is largely the same for children with special needs as it is for other children, except that at the outset a "more thorough intake process" may be used, with parents sometimes required to provide more medical records and information. Peterson said she expects the university to continue supporting the center at its present level after the federal grant expires.

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IBM

IBM employees who have children with disabilities can obtain financial assistance for health care expenses not covered under the company's medical plan, including health care provided at child care facilities.

The IBM Special Care For Children Assistance Plan reimburses part of the expense for the care of children who are mentally retarded, emotionally disturbed, physically handicapped, or have a developmental or cognitive disorder.

Established in 1966, the plan provides a maximum lifetime benefit of $50,000 per child, up to age 23. Applications are accepted from employees who have exhausted all other sources of financial aid, including that available from local, state, and federal agencies.

Most of the 2,000 applications for assistance in 1990 were approved, according to IBM spokesman John Boudreaux. Conditions covered by the plan include hearing or speech impairments, learning disabilities, visual impairments, anorexia or bulimia nervosa, substance abuse, behavioral or emotional problems, and orthodontia related to surgery for an abnormality. Children may receive treatment at licensed clinics, special day care or residential care facilities, special schools, camps, halfway houses, or substance abuse facilities. The employee pays a $150 annual deductible, and the company reimburses the employee for 80 percent of the remaining eligible charges.

Leave Policies Help

Employees who have children with special needs also can benefit from IBM's personal leave program, under which workers can receive unpaid leaves of absence of up to three years, and are guaranteed a job when they return. Such personal leave is in addition to the company's illness and accident leave, which includes full salary during the time that a woman's doctor certifies that she is disabled due to her pregnancy.

IBM, headquartered in Purchase, N.Y., employed about 200,000 people in the United States in 1991. At any given time, about 2,500 employees are on personal leave, and about 90 percent are women, according to Kathleen A. Ryan, staff communications specialist. The most-cited reason for taking personal leave is to stay home with a young child, Ryan told BNA. To maintain their job skills, employees on extended leave must be available for part-time work during their second and third years away from their job.

Children may receive treatment at licensed clinics, special day care or residential care facilities, special schools, camps, halfway houses, or substance abuse facilities.

The child care center is located in a public elementary school that has ramps and other equipment that make it accessible to children who use wheelchairs and who have other disabilities.

Dependent Care Initiative

The expansion of a day care center in Montgomery County, Md., that is fully accessible to children with disabilities is among the projects being financed with $25 million IBM earmarked in 1989 for projects to increase the availability of child care and elder care where its employees live and work.

The child care center is located in a public elementary school that has ramps and other equipment that make it accessible to children who use wheelchairs or have other disabilities.

In addition, one room is used to care for children who become mildly ill while they are at the center.

About three or four of the 125 children enrolled in the center have special needs, according to Delores Harris, director of the Academy Child Development Center/Stone Mill, a private non-profit organization that owns the center and several others. Disabilities of children who have attended the Montgomery County center include legal deafness, attention-deficit disorders, asthma that requires medication, and learning disabilities, according to Marilyn Fleetwood, administrator of the academy and director of its board.

Fleetwood, who has a master's degree in special education and is certified to teach kindergarten through grade 12, told BNA her background in special education enables her to work with parents whose children have various disabilities to establish individual programs that enable the children to attend the center.

The center probably could accommodate any disability except one that would require a staff member to be with the child at all times, Fleetwood said. Even in such a circumstance, the center might accept the child if the parents or some organization paid the salary of a nurse or aide to be with the child, she added.

Low child/teacher ratios—3:1 for infants; 6:1 for toddlers; 10:1 for preschool children; and 13:1 for school-age children—plus the availability of extra staff members during certain times of the day enhance the center's ability to serve children with special needs, Fleetwood said.

Although the center is open to all children in the community, children of IBM employees receive preference for 48 percent of the available spaces, as part of the firm's funding arrangement. IBM helps fund several child care centers in locations around the country that have large concentrations of IBM employees.

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TRIDENT REGIONAL MEDICAL CENTER

Strong financial backing, convenient location, and professional management have enabled the Trident Child Development Center for children of employees at Trident Regional Medical Center, in Charleston, S.C., to admit children with a wide variety of special needs, according to Cathy Brewer, child care center director.

The child care center is operated by Corporate Child Care Inc., of Nashville, Tenn., under contract with the medical center.

Brewer, who has 15 years experience in the day care field, thinks having special needs children enrolled at the center has been good for the staff. "These difficult children are a great challenge for teachers to learn. They inspire them to grow. It has helped also to improve activity planning," she noted.

"These difficult children are a great challenge for teachers to learn. They inspire them to grow. It has helped also to improve activity planning," she noted.

She acknowledges that being only "a stone's throw from the emergency room," a luxury not enjoyed by many employer-provided child care centers, has made it easier for the Trident center to accept children with disabilities. For example, the next child with special needs to be admitted is expected to be an infant who is connected to a heart monitor.

Current and recent enrollees include a deaf child, two hyperactive children with attention-deficit disorders (ADD), and a child with spina bifida, a congenital defect characterized by imperfect closure of part of the spinal column.

To be able to communicate with the deaf child, her teacher took a sign language class on her own time, and now teaches the other children songs in sign language. Because the child's speech therapist's office is only a block from the center, her mother, a pharmacist at Trident medical center, is able to drop her off at the office for therapy two or three times a week, and someone there brings the child to the center after the therapy sessions.

The child and her teacher were featured in a recent issue of the center's bi-monthly newsletter—*Partners*—that is distributed throughout the hospital.

A child with spina bifida also attended the center for six months recently. Because he urinated through his naval, someone had to press on his bladder to make sure it was properly emptied. Although center staff members were "always afraid that he might get hurt," no accidents occurred and they enjoyed having him at the center.

ADD Studied

One of the two "very hyperactive" children with attention-deficit disorders had been expelled from three child care centers, Brewer said, in part because they were not able to provide the individual attention he needed. Brewer said the center has informally established a project to learn about attention-deficit disorders, so its staff can help the children and serve as a resource for parents.

Brewer said she has learned that children with ADD "definitely need" to be given "different kinds of commands" because they often become frustrated and have "trouble moving from one activity to another."

Brewer said she has learned that children with ADD "definitely need" to be given "different kinds of commands" because they often become frustrated and have "trouble moving from one activity to another." For example, the teacher of the child who had been expelled from other centers has found that giving him "advance notice" makes it easier for him to end one activity and start another, Brewer said.

Brewer said she always consults with the pediatricians of children with disabilities before accepting them at the center. In addition, before accepting the child with spina bifida, she had Corporate Child Care confirm that its insurance would not be affected if the child were enrolled.

Because the child care center is associated with a hospital, physicians and other health care professional conduct seminars for teachers, parents, and other members of the community on various health-related topics, including those regarding children with disabilities. For example, a pediatrician discussed ADD at a recent session. Teachers are paid for attending the evening seminars, and child care is provided while they are conducted.

Although open for less than a year, the Trident child care center, which currently serves 92 children and is open 13½ hours a day, is expanding to include an accredited kindergarten starting this fall. This will raise total enrollment to 134. The hospital established the center primarily to improve its recruitment and retention efforts. Many hospital employees need only part-time child care and the center can provide such flexible arrangements.

The medical center provides the child care center with a new, rent-free facility, food, utilities, maintenance, housekeeping, and paper supplies.

Tuition is used exclusively to hire qualified staff and to provide training. As a result of the hospital's support, the center maintains a 5:1 child/teacher ratio for infants and 7:1 for toddlers, far below the 8:1 and 15:1 figures required by the state.

Because the center is located across from the hospital employees' parking lot, parents are able to visit their children at lunch time and other work breaks, Brewer noted.

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...parents are able to visit their children at lunch time and other work breaks...

STEELCASE INC.

About 4 percent of the Steelcase Inc., employees who use the firm's in-house child care resource and referral service have children with disabilities, according to Deborah VanderMolen, supervisor of the company's counseling department.

The service is available to all of the office furniture manufacturer's 9,000 workers in Grand Rapids, Mich. Most of the service's staff have master's degrees in early childhood development, and participating day care providers must meet criteria that exceed state requirements, VanderMolen told BNA. In return, Steelcase: (a) provides free classes in administering CPR to children; (b) presents workshops on child care; (c) lends providers equipment for infants; and (d) maintains a lending library for parents and day care providers.

The service "always" tries to provide parents "multiple referrals," VanderMolen said.

Disabilities of the children whose parents have used Steelcase's resource and referral service include hyperactivity, blindness, deafness, use of wheelchairs, and heart problems that require monitors. Although the firm does not know how many child care requests it receives each year from parents of children with special needs, VanderMolen said requests "occur every year, although probably not on a monthly basis." The service usually is successful in finding appropriate care for children with disabilities, although it once "took longer" to find care for a child with a communicable disease, she said.

In 1990, the service found day care for every child with special needs whose parent used it. The service also helps parents who have disabilities with their child care problems. For example, the service found a child care facility on a bus line for a mother with epilepsy who cannot drive a car.

Some providers charge more to care for children with special needs, with the fees depending on the level of individualized care required.

Multiple Referrals Essential

The service "always" tries to provide parents "multiple referrals," VanderMolen said. In one case over a year ago, the service found care for a child with a condition that caused his skin to be almost "inside-out," and required him to have medication applied four times a day, she recalled. The service was able to refer the child's parents to two individuals who agreed to take care of the child, one of whom the parents later selected.

The service also provides a 'round-the-clock sick-child care and emergency child care referral service, which often proves especially helpful for parents of children with disabilities. VanderMolen and her staff wear beepers, so that if, for example, parents discover at 2 a.m. that their child care arrangements have failed or their child is ill, they can obtain the names of child care or health care providers willing to care for their child.

Finding day care for children with special needs "can take us weeks, sometimes longer, and we have our finger on all of the resources," VanderMolen said, adding that she understands why parents who get less help than Steelcase employees often conclude that "this is just not worth it."

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LOS ANGELES WATER AND POWER

The 11,000-employee Los Angeles Department of Water and Power (DWP), the largest municipal utility company in the United States, provides specialized resource and referral services for workers whose children have special needs.

Although all DWP employees are entitled to use the resource and referral service with which DWP has a contract, workers who have children with disabilities and those in other difficult or stressful situations receive additional help, according to Yolie Flores Aguilar, director of DWP's resource center for parents.

Whereas other parents must contact the resource and referral service directly to discuss child care, Aguilar's staff, which has background and experience in social work, determines for parents of children with special needs which providers can enroll their children. As a result, such parents contact and negotiate arrangements with only those providers that have spaces available and can meet their children's special needs. The DWP parent resource center also direct parents who need assistance to "financial resources and life-management" counseling, Anguilar said.

Her office also serves as an advocate for parents with their supervisors.

Her office also serves as an advocate for parents with their supervisors. For example, Aguilar recently discovered after locating appropriate care for a 14-year-old with a heart problem that the care was not always available while the parent was at work, so she contacted the worker's supervisor to work out a suitable arrangement. Although the supervisor did not agree to all of the requests Aguilar presented, approval was given for the parent to change his work schedule during the summer. Aguilar said her office is successful making such arrangements about "half of the time."

A nurse counsels parents of children with disabilities, parents of premature babies, and pregnant employees two days a week at the parent resource center, Aguilar noted.

Parents at Work, a four-page quarterly DWP newsletter, includes a calendar of events for parents that lists activities of a support group for parents of hyperactive children.

DWP purchases space for employees' children from three off-site child care centers and is constructing two on-site centers, both of which are designed to accommodate children with disabilities, in addition to other children. One of the off-site centers is located at the Pediatric and Family Medical Center, which has a program for children with special needs. Children who attend the medical center program can also enroll in its child care program. Aguilar said at least two children of DWP employees who have special needs are enrolled in the center.

The new centers are being built to exceed all codes that apply to serving children with disabilities, Aguilar said. The centers' design result in part from planning discussions with parents, many of whom stressed the need to serve children with disabilities, she noted.

One goal of the new centers is "not to turn away" children with special needs, Aguilar said, adding that they will make "every effort possible to accommodate" such children and will make most enrollment decisions on a case-by-case basis.

The center staffs will receive in-service training about special needs through a series of on-going workshops, Aguilar said, especially if children with special needs are enrolled in the new centers.

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