

## BusinessWeek

### *A Booming Business Serves Special Needs Families*

Employers, financial services firms, and consultants are helping families with disabled members qualify for financial and educational aid



Douglas, with his family, has just located benefits for 7-year-old Stephen (center) Billy Delfs

By Toddi Gutner  
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## Managing Through a Crisis

Only recently, Aron Douglas learned that the intensive and expensive daily therapy for his seven-year-old autistic son, Stephen, is tax-deductible, that he should set up a special-needs trust for Stephen, and that states other than his own—Ohio—offer autism scholarships to help pay for specialized therapies.

Through Ernst & Young's EY/Assist Parents Network, Douglas, finance director at EY's Cleveland office, participates in two monthly teleconferences with experts. One is focused on a specific disability; the other addresses general topics such as creating an



individual education plan, the document schools rely on in serving children with special needs. "The ability to speak with other parents who have older children and have been through the school process before has been incredibly helpful," says Douglas.

In the last couple of years, U.S. corporations have been paying a lot more attention to the 54 million adults—nearly 20% of the nation's population—that have mental or physical disabilities. And with 6.3% of American children between the ages of 5 and 15 suffering from a disability, companies are also focusing on working parents who care for them. It's to their benefit: Employers suffer lost productivity when workers take time off to tend to the needs of affected children and adult offspring.

In what have become the latest benefit programs, companies including PepsiCo ([PEP](#)), KPMG, JPMorgan Chase ([JPM](#)), and Northrop Grumman ([NOC](#)) are offering services that range from parent networks to Web seminars to meetings with financial planners and educational consultants. In addition, a growing crop of advisers is emerging to guide families through the financial, medical, and educational labyrinth. "There is no national network to tap to get information, so private industry is stepping in to fill the gap," says Charlie Hammerman, president of the Albertson (N.Y.)-based Disability Opportunity Fund, an investment and financial-services firm focused on special needs.

The demand is huge. While federal laws govern disability rules, each state has different programs to aid families. Mess up the financial planning, and it could mean the loss of a disabled family member's ability to qualify for Medicaid and Supplemental Security Income. These programs pay for most medical care, housing, and other community services. But under federal and state laws, those 18 or older with disabilities can't receive such benefits if their assets exceed \$2,000. To navigate around that, parents must set up a special needs trust so a child doesn't own assets. The trust can accept and invest inheritances, and thereby supplement government benefits.

With such a tricky issue, researching an adviser's experience and training is crucial. "This kind of financial and legal planning and educational support is so important that you need to look for advisers the way you look for doctors for your children," says Nadine Vogel, president of Mendham (N.J.)-based Springboard Consulting, one of the new firms that helps companies market products and services to people with disabilities and to their families. Vogel—the mother of two daughters with learning disabilities and other special needs—says that since laws change constantly, you should ask about advisers' certification processes and how often their training is renewed.

Outside of corporate programs, specialty units such as Merrill Lynch ([BAC](#))'s Special Needs Financial Services group, MetLife's MetDESK Division of Estate Planning for



Special Kids, and MassMutual Financial Group's SpecialCare group have dominated the market. They work directly with families on the complex special-needs financial planning process.

More recently, a host of smaller advisory firms have jumped into the arena. They focus on helping families locate resources to pay for medical and educational costs as well as plan for the future. "Finding programs is a complicated maze, and parents don't know about them or have time to search," says Mary Anne Ehlert, a Lincolnshire (Ill.)-based planner with expertise in disabilities. Last November she launched Protected Tomorrows, a national network of advocates to help families find those resources. For an annual retainer of about \$2,000, or an hourly rate of \$150, Ehlert's advisers find programs such as state scholarships to pay for autism therapies or grants to do home renovations for a person with cerebral palsy.

## State Mandates Help

More help is also becoming available in securing health claim reimbursements. While companies have long been around to help individuals through the process, Myrna Cortez, president of ProMediClaim, a medical-claims advocate based in Evanston, Ill., has seen an increase in families seeking help for members with special needs.

Jeff Sell, vice-president of advocacy and public policy for the Autism Society of America, has 14-year-old autistic twins. From knowledge he picked up at his job, he hasn't needed an advocate. Sell notes that 42 states require some sort of autism treatment to be covered—or have a bill introduced, or pending, to require it—up from just one state five years ago. Though nearly every health claim he put in for his children was at first denied, he appealed and ultimately won coverage. "Most people don't follow through with the appeal process," he says.

The growing network of support services for the disabled can no doubt be a big help. Even so, says Vogel, "caring for this population is about asking questions all the time. Ask, ask, and ask again."