

## **The New York Times**

Tuesday, August 12, 2008

By MICHAEL T. LUONGO

[Business travel](#) is never easy for a parent. But business travel for the parent of a child with special needs is another story.

That is why Sarah Barnes, whose 7-year-old son is [autistic](#) and has [hearing loss](#), had a mixed reaction when her boyfriend told her he had been promoted.

“That means he’s going to have to travel,” she remembered thinking. “It was the first thing that popped into my head,” though she hastened to add she was happy for him.

Ms. Barnes, a nurse at the University of California Davis Medical Center in Sacramento, said she worried about juggling schedules for her son, Shane, who, she said, was born prematurely and has “always had special needs.”

Figuring out how to care for special needs children, whose problems range from autism, physical disability, developmental issues, hearing impairment and retardation, can be difficult, especially if the children need 24-hour care and are on strict schedules.

“Traveling, in general, puts pressure on the family unit, but when you have a child with a disability, there are very often larger issues,” said Philip H. Levy, the president of YAI/National Institute for People with Disabilities Network, an organization based in New York for people with disabilities of all ages across the United States.

Jacqueline Kotler, an executive assistant at Doyle Kos, a [music](#) management company in New York, has a son, Zak, 3, who has Prader Willi syndrome, which she said is a rare genetic disorder that “affects the hypothalamus, so it affects temperature regulation, appetite.” If left alone around food, she said, “he can literally eat himself to death.” His brain, she said, “will not tell him to stop.”

Zak's eating times are scheduled every three hours, with strict portions. Ms. Kotler said a recent trip to Austin, Tex., for the [South by Southwest Music Festival](#) involved preparing "food for four days, and putting everything into a grid, putting everything into the freezer, portion controlled."

Ms. Kotler said that because both she and her husband travel, they stagger their business trips. Family members and a nanny help, but, she said, "one hurdle that we're still facing as far as going away — or that myself, or my husband or my nanny is not there — is that Zak gets a hormone shot every night, and we're the only three people that know how."

Some special needs children cannot understand that a parent is away. "When you have a child who doesn't speak, I can't explain anything," said Candi Nichols Carter, a television producer in Chicago, and the creator of the children's entertainment company It's Hip Hop, Baby! "I had to go to Vegas for four days to work on a show," she said. "I can't explain that to him, that 'Mommy's going to be gone for four days.' The next day, he wakes up and his mother is just gone. It's got to be traumatizing."

Ms. Nichols Carter's 5-year-old child, Emerson, presents a multitude of challenges. In an e-mail message, Ms. Nichols Carter wrote: "Emerson is a child with a mental disability. We found out a year and a half into his life that he was born with a chromosome abnormality. As a result he had many physical problems early on and currently struggles with a severe speech delay."

While language problems heighten issues for children like Emerson, Mr. Levy said, "children with disabilities will very often have more [anxiety](#) around the separation." He advises business travelers to "maintain some type of continuity and consistency," by building communication into travel schedules, such as dinnertime calls on a speakerphone, a technique Ms. Nichols Carter uses.

Some parents completely reschedule their jobs around their children's needs.

Ms. Barnes said via e-mail that when her boyfriend, Chad Watson, took his new position, he negotiated a contract with "total control over dates of business travel with at least two weeks notice prior to travel." And after Shane was born, Ms. Barnes said she knew she would have to find a job working with his schedule. She said she started nursing school while Shane was in the hospital "because I knew I needed a schedule change." She added that she and Mr. Watson are "like ships passing in the night on the three nights that I work."

In her family, Ms. Nichols Carter is the road warrior, not her husband. Beyond daily needs, Emerson sees several specialists. "We both can't have crazy work schedules and have to do all those appointments," she said.

Family involvement, often from grandparents, can also help. Ms. Kotler said her parents and her in-laws have taken care of Zak. Early on, Ms. Barnes's parents helped, becoming part of what she called Shane's "tag team."

Baby sitters can fill gaps, though qualified help is hard to find. One option is SitterCity ([www.sittercity.com](http://www.sittercity.com)), based in Chicago. Genevieve Thiers, who started the service in 2001, described it as "like Match.com, but for parents and caregivers across the country."

She said the service has "hundreds of thousands of caregivers" across the country, about 30,000 of whom can baby-sit for special needs children. Ms. Barnes uses Sittercity and said she is "in the process of finding one that works for us."

Other aids include Forms4Parents ([www.forms4parents.com](http://www.forms4parents.com)), started about a year ago by Linda Kagan, a lawyer in New York. Parents can use the service to fill out forms with information about a child's special needs, medical and other information, and then print

out those document for caregivers. Ms. Kagan said that “paranoia, a dose of lawyering and a dose of parenting gave rise to this idea.”

Care for special needs children can be expensive. Skilled baby sitters charge more, usually “an extra dollar or two more per hour,” according to Ms. Thiers.

Beyond schedule complexities and costs, Mr. Levy said taking care of special needs children puts significant pressure and guilt on parents and siblings. He said that divorce rates can be higher among such parents, but added, “If you get through the initial issue of pressure, it can bring the family closer together.”