

# The New York Times

## Bypassing the Roadblocks of Autism



Courtesy of the Delgiudice-Asch family  
Andrew Asch, 16, has autism, but his parents have tried not to limit his travels, which have included ski trips to Colorado and visits to the Jersey Shore.

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Published: September 14, 2008  
New York Times, Sunday Edition, Travel Section

WHEN Victoria Berrey took a cruise with her mother and sister three years ago, she returned to her home in Santa Clarita, Calif., with one regret: She'd never be able to do a trip like it with her own children, both of whom have autism. "I worried about the confined quarters and the need for the boys to sit still in the dining room," said Mrs. Berrey, whose older son, Miles, now 12, is on a restricted diet, and whose younger boy, Mathew, 8, has difficulty with any disruptions in routine. "Where would I take Mathew if something happened and he started yelling? What if one of them fell overboard?"



Victoria and David Berrey found a cruise with special arrangements for their sons, both of whom have autism.

But last March Mrs. Berrey and her sons did enjoy a cruise, a three-day sail on a Royal Caribbean liner with special arrangements for people who have autism. At boarding, the 11 families who had booked the "Autism on the Seas" package through Alumni Cruises didn't have to wait in line, and they were able to do the muster call in a private conference room rather than crowd on deck with the thousands of other passengers.

The group sat together at meals, so when one of the kids got antsy or let out a holler, there were no stares or glares or why-can't-you-control-your-child lectures. Mrs. Berrey was even able to drop off her boys at the kids' club where the staff had been specially prepped. "I got to experience what other parents experience all the time," she said.

For most people, family vacations amount to almost a right. But for those grappling with autism — a brain disorder that affects one in 150 children and is four times more likely to afflict boys than girls, according to the Centers for Disease Control and Prevention — travel is a trickier proposition.

The 1.5 million Americans diagnosed with autism, also known as autism spectrum disorder or pervasive developmental disorder, have impaired abilities to communicate and interact socially, with cases ranging from those who cannot speak and live largely cut off from the world around them to highly functioning individuals who can express themselves extremely well, though they might have trouble with back-and-forth conversation; many have narrowly focused interests (an obsession with fans or train timetables, for example), or display unusual behaviors like the repetition of just-heard words, or the avoidance of eye contact or of being touched.

Yet for every parent who decides they're better off staying at home with a child who might have a meltdown if someone accidentally brushes against him at a hotel breakfast buffet, there are others who are determined to hit the road, particularly if there are nonautistic siblings in the equation. And with Americans who have disabilities spending \$13.6 billion annually on travel in the United States (not including the caregivers and family members who often accompany such individuals), according to a 2005 Harris Interactive poll for the Open Doors Organization, a small but growing number of tour operators, travel agents and resorts are offering specially geared getaways.

The Autism on the Seas trips from Alumni Cruises, a booking agency in Shelton, Conn., have tripled the last two years, far outpacing the company's beading- and home school-themed voyages and now accounting for almost half its revenue. Adam's Camp, a Colorado organization that provides camp-style sessions at Snow Mountain Ranch, in Granby, for children with disabilities and their families, added a fifth week this year and is considering a sixth because of the increased demand from the families of children with autism. It has also begun a program on Nantucket and hopes to add additional sites.

At Smugglers' Notch Resort in Vermont, three-quarters of the participants in a program for people with special needs are autistic, and that number increases every year, according to Kris Connolly, manager of adaptive programs at the resort, who will provide one-on-one care if required, or steer a child with autism to a group of kids who are the same developmental, as opposed to chronological, age. "We might spend an extra 20 minutes at the pool if the water is calming to a child, or he enjoys the feeling of buoyancy," she said. "If we see real enjoyment at the swing set, that's where we'll take extra time."

And while hotels and resorts have focused on accommodating guests with physical handicaps since the enactment of the Americans With Disabilities Act in 1990, according to Scott Berman, a hospitality and leisure analyst at PricewaterhouseCoopers, the 300-hotel chain Microtel Inns & Suites, which has won awards from disability-rights organizations for going above and beyond the requirements of the law to welcome guests with physical differences, includes discussions of hidden disabilities like autism in staff training.

"There's been a sea change in terms of awareness," said Marguerite Colston, spokeswoman for the Autism Society of America, who credits celebrities like the former Miami Dolphins quarterback Dan Marino and the actress Jenny McCarthy, who have spoken out on behalf of their own children and those like them, with helping spread the word. "It used to be that when people heard the word autism, they thought 'Rain Man,'" Ms. Colston said, referring to the 1988 movie in which Dustin Hoffman plays an institutionalized autistic savant. "Now they realize there's a broader range." And with more and more children being diagnosed with autism — now the fastest-growing developmental disability in America, according to the society — "it's much more likely that any given person will know someone with autism," she said.

All of which is not to suggest that vacations with an autistic child are easy. The very idea of travel — the chance to see new places, try new foods, experience new cultures — is directly at odds with the needs of many people with autism, who require well-established, strictly observed routines to feel secure.

And while the airport experience since 9/11 has become much more trying to all of us, it can be extremely challenging for someone who has inherent difficulty waiting or standing in line, not to mention answering questions posed by a security guard. "If a guard asks, 'Did you pack your own bag?' someone with autism might repeat the question, or just repeat the word, 'bag,'" said Dr. Melissa Nishawala, director of the Autism Spectrum Disorders Service at the New York University Child Study Center. "The child might read 'dangerous explosives' on a sign somewhere in the airport and start repeating those words. Loudly. In line."

Then there is the plane ride itself. "By the time they get on the plane, the parents and the child are stressed out," said Dr. Ron Balamuth, a New York psychologist who specializes in working with children who have developmental disorders. "For a kid who needs constant stimulation, that's like putting him in a flotation tank."

In June, a mother and her young autistic son were kicked off an American Eagle flight departing from Raleigh-Durham in part because of the child's behavior. An item about the incident on the Chicago Tribune's blog drew 221 posts by the end of the day — almost twice as many in support of the airline as sympathetic to the family.

Parents who travel with autistic offspring employ many strategies. They pick destinations that will appeal: a resort with a pool if the child loves water, or Disney World if he has a fixation

with "The Lion King." They role play with their child before departure to prepare for the experience. "I had a family with a child who had tremendous difficulty waiting in lines, waiting for anything," said Dr. Balamuth. "They turned their house into a flight gate. The family lined up with suitcases, they took off their shoes, they play acted the whole thing."



The Delgiudice-Asch family with Andrew, second from left.



Right, courtesy of the Cerabone family  
Left, the Cerabones at home in Staten Island.  
Right, Anthony Cerabone, 15, on vacation in Vermont.

Itineraries, even daily schedules, reviewed in advance help autistic travelers know what is going to take place, and when. "If a child can read, it's words on a page; if not, it's pictures," said Lisa Goring, director of family services for Autism Speaks, an advocacy group. With her own son, Andrew, 12, Mrs. Goring ticks off activities as they occur. "He's anxious if he doesn't know when an activity will end," she said.

Parents carry a letter from their child's doctor explaining the condition (to whip out at the airport or to present at guest relations at Disney World, where it can secure a pass to circumvent long lines). They take along

familiar toys and a DVD player so favorite movies can be watched en route. And if the child is on a gluten-free, casein-free diet (thought to relieve allergies and other medical ailments that might be distracting to someone with autism), they cart along a lot of food, too.

If parents find a destination that works for their child, they often return. Anthony and Felicia Cerabone of Staten Island bought a timeshare at Smugglers' Notch, where their son, Anthony, 15, has participated in the resort's SNAP program for people with special needs for 10 years. "He knows that every July we go," said Mrs. Cerabone. "He knows that every day he goes to the camp. By now it's routine."

Gina Delgiudice-Asch, a rheumatologist, and her husband, Will, a high-school math teacher, from Princeton, N.J., have managed to range farther afield with their two children, even though their son, Andrew, 16, has autism, Dr. Delgiudice-Asch said from Avalon, N.J., where the family rented a house at the shore for a week at the end of June.

Sometimes she or her husband will take a one-on-one trip with their 13-year-old daughter, Samantha, a nationally ranked junior tennis player — on a recent jaunt to Los Angeles, mother and daughter visited the set for "Ocean's Thirteen" and ducked in and out of shops on Rodeo Drive. "With Andrew, everything has to be more planned," said Mrs. Delgiudice-Asch.

But often the family travels as a pack, taking along a familiar babysitter or a teacher from Andrew's school to help. They have vacationed everywhere from Winter Park, Colo., where instructors at the National Sports Center for the Disabled had Andrew on skis four hours a day, to Costa Rica. "It was hard when we got to the resort, and they didn't have a grilled cheese for him right away," Dr. Delgiudice-Asch acknowledged. "But he got the hang of it."

They go to family-oriented resorts rather than exclusive places where "we might be impinging on other people's vacation," she said. And they stick to coach after a bad experience flying first class from California to Cabo San Lucas, Mexico, when Andrew, who was 6 at the time, started crying and a passenger complained to the flight attendant. Though they'd like to see Europe, they haven't gone as a family. That's not because Andrew, by now a seasoned traveler, couldn't handle the flight, but because he would have too much difficulty with the time difference, his mother said. "But we're still doing fun things on vacation as a family," she said. "We're not letting autism back us into a corner."