Leslie Newport (left) of Brielle plays with her 8-year-old autistic son on the playground of the Douglass Developmental Disabilities Center at Rutgers. Below, Sen. Robert Menendez, D-N.J., who was at the center on Thursday, visits with Newport and her son.
Progress, but far to go in treatment

By RICK MALWITZ
STAFF WRITER

RUTGERS — When the Douglass Developmental Disabilities Center began in 1972, accepting nine children who had been diagnosed with a form of autism, little was known about the disability.

Sandra L. Harris, the center's executive director, recalled a call from one parent who wanted to enroll her child.

"She said her daughter was very artistic," Harris said.

Since then parents and advocacy groups have raised awareness of autism, which is diagnosed in one of every 110 children in the United States, and one in 94 in New Jersey.

To mark the beginning of Autism Awareness Month, the center, which now has 70 children diagnosed with autism, played host to U.S. Sen. Robert Menendez and Rep. Frank J. Pallone Jr., both D-N.J., thanking them for their support of the comprehensive health care legislation.

Menendez said he was able to add an amendment to the legislation that would require, beginning in 2014, state-based health insurance plans to include certain levels of treatment for persons with autism.

The legislation would come close to matching legislation already in 15 states, with three states on the verge of passing similar reforms.

"I've heard from so many parents who have shared their heart-wrenching struggles, not only with the

See Autism, Page A5
disease, but with the complexities of a health care system that often leaves them feeling lost," he said.

While most of his remarks were from a prepared statement, two mothers of sons diagnosed with autism told their stories of the complexity and the cost of their care.

Leslie Newport of Brielle spoke about the challenges of caring for her 8-year-old son. In his first year, he was an affectionate child, with no noticeable difficulties.

By the time he was 2, he would withdraw to the corner of a room, not acknowledging his mother. At 8, he cannot speak or follow basic instructions and is taken to the bathroom every 15 minutes.

Following the news conference, the lawmakers, their staffs and members of the media observed the boy at play. While he appears normal, he lacks social skills.

His mother recalled that before his diagnosis, she spent countless hours trying to learn what was wrong. "I was in tears every night," she said.

She estimated she spent $100,000 out-of-pocket before her son's third birthday. When she has someone care for him, she pays a minimum of $30 an hour for child care. She pays more if they have been trained to care for children with disabilities.

Tracy Gencarelli of Parsippany spoke about the needs of her 14-year-old son, Matthew. "My biggest concern is adulthood. He only has seven more years here," Gencarelli said of the school, located on the Douglass campus.

Last week the school was closed for spring break, and Gencarelli cared for her son full time. "By the end of the week, I was exhausted," she said.

The costs to have their children schooled here and transported here are absorbed by their local school boards. Beyond the cost of schooling, parents pay what their insurance carrier does not cover. Newport said she has been rejected numerous times when she has sought specialized care. She said she gets $180 a month for respite care, which is supposed to cover the cost of a child-care provider.

"I can go through that in the first two days of the month," said Newport.

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