

Autism Services Don't Reach Certain Families

BY DIANA MAHONEY
New England Bureau

MONTREAL — In children diagnosed with an autism spectrum disorder, those with Asperger's syndrome, minority children, and those whose families do not follow one of the major autism treatment approaches fall behind others when it comes to early intervention services, service intensity, and family involvement in providing treatment services, an analysis shows.

The findings highlight the need to develop family-level interventions for disseminating information, enhancing decision making, and supporting parents to ensure adequate access to effective service elements for all children with an autism spectrum disorder (ASD), Kathleen Thomas, Ph.D., said at the 5th International Meeting for Autism Research.

As part of a 4-year study aimed at assessing family and child use of effective autism program elements funded by the National Institute of Mental Health, Dr. Thomas and her colleagues at the University of North Carolina at Chapel Hill recruited a sample of 383 families with a child aged 11 years or younger with an ASD diagnosis to participate in a combined telephone/in-person survey.

Sixty percent of the sample was obtained through the university's Neurodevelopmental Disorders Research Center Subject Registry; 40% was obtained through direct recruitment from schools and developmental services agencies within the state.

The survey assessed demographics, access to services, use of services, payment for services, and overall satisfaction with services. The response rate among recruited families was 91%. The mean age of the children represented in the survey was 7 years; 71% of the children were white, and 87% were male.

Most families (58%) reported having private insurance, 21% received Medicaid alone, and 8% had both. About 70% of the children had a diagnosis of typical autism, 21% were diagnosed with Asperger's syndrome, and the rest had other diagnoses along the autism spectrum. The average age at diagnosis was 4 years.

Of the families participating in the survey, 95% reported involvement with a major autism treatment approach. "Because the participants were from North Carolina, most of the families use TEACCH [Treatment and Education of Autistic and Related Communication Handicapped Children, which was developed at the University of North Carolina and was the first statewide program for treatment and services for people with autism], although a fair number also reported using programs built on the 'applied behavior analysis' model, as well as some others," Dr. Thomas said. "Five percent of the families said they were not really following any formal approach."

On average, the children were receiving four service sessions a week in school and eight service sessions a week out of school, four of which the family was providing.

An 18-item measure was used to evaluate family well-being and use of and satisfaction with service elements, including social therapies, specialist care providers,

medication therapies, and child care.

"Our goal was to look at associations between child/family characteristics and different service elements," Dr. Thomas said. "We saw that children from minority families were getting diagnosed at a later age, they were receiving fewer services, and the proportion of family involvement in services was lower than the average."

In the families that didn't follow one of the major treatment approaches, "there was no association with age at diagnosis,

but they also received fewer services overall and had less family involvement," she said. Children with Asperger's syndrome were diagnosed later than were those with typical autism; those with a diagnosis of mental retardation were identified earlier.

Nearly 15% of the respondents reported not being satisfied with the services they were receiving, even though they were receiving a higher proportion of services and had more family involvement.

Among the enabling characteristics, nei-

ther family stress nor ability to pay for services was associated with any differences in the receipt of or family involvement with services, Dr. Thomas said. However, "children who were diagnosed at a younger age were receiving more service sessions in school than those diagnosed later."

In addition, screening efforts should cast a wider net to include those children who may not fall within the typical autism diagnosis but who could benefit from early identification and intervention, she said. ■



The advertisement features a collage of five photographs: a young man smiling, an older male doctor with a stethoscope, a medical device, a female doctor with a clipboard, and a female patient smiling. Below the photos, the word "Us" is written in a large, blue, serif font, and the word "Them" is written in a smaller, blue, serif font to its right. A small, 3D-rendered wooden crate is positioned above the word "Them". Below the text, the slogan "Don't be left all alone." is written in a blue, sans-serif font. At the bottom right, the "LASERSCOPE Aesthetics" logo is displayed, with "LASERSCOPE" in a bold, blue, sans-serif font and "Aesthetics" in a smaller, blue, sans-serif font with a yellow starburst. At the bottom left, a small copyright notice reads: "© 2006 Laserscope. Gemini and the Laserscope logo are trademarks of Laserscope. All rights reserved."