

Autism Services Not Reaching Some Families

Survey uncovers barriers to earlier intervention for children with Asperger's and minority children.

BY DIANA MAHONEY
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MONTREAL — Among 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 assure 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; forty percent 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.

Ninety-five percent of the families participating in the survey 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. "Surprisingly, 5% of the families said they were not really following any formal approach."

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

An 18-item measure was used to evaluate family well-being as well as use of and satisfaction with different 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. "What we saw was 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."

Additionally, among the families who 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, while 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.

"Interestingly, this group was receiving a higher proportion of services and had

more family involvement," Dr. Thomas noted.

Among the enabling characteristics, neither 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," she said.

The findings uncover some important barriers to early intervention, "which gives us some idea of where we need to focus attention to be sure to get to kids at an earlier age," Dr. Thomas said.

"Access to care is more limited for minority children and those whose families are not using a formal approach to care. We need to find a way to focus in on these groups. Clearly, more families need better information about the autism services available and information about how to choose the best treatment option."

Also, screening efforts need to 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.

Finally, "the results demonstrate that families with autistic children are devoting a tremendous amount of time on the provision of services to their children," Dr. Thomas said.

"This should be taken into account in the design of programs and policies to make sure the families are getting the support and education they need to be able to do this." ■

Repetitive Behaviors of Autism Linked to Mood Problems

BY DIANA MAHONEY
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MONTREAL — Comorbid mood and behavior problems that are present at an early age in children diagnosed with an autism spectrum disorder are associated with the frequency and severity of restrictive, repetitive, and stereotyped behaviors, a study has shown.

But those comorbid behaviors—including anxiety, hyperactivity, oversensitivity, and conduct problems—are not related to social or communication diagnostic criteria, Robin L. Gabriels, Psy.D., said at the 5th International Meeting for Autism Research.

Previous studies have demonstrated that people who have autism spectrum disorders (ASD) are at risk for various comorbid behavioral and psychiatric disturbances.

But at this point, it remains unclear whether such problems occur independently or result from pathologic processes that lead to autism, Dr. Gabriels said in a poster presentation.

And while it has been hypothesized that these comorbid problems somehow relate to the range of restrictive and repetitive behaviors and interests that characterize autism—including inflexible adherence to specific, nonfunctional routines or rituals,

stereotyped and repetitive motor mannerisms, and self-injurious acts—data are lacking on how the specific behaviors relate, she said.

In an effort to gain insight into this association, Dr. Gabriels of the University of Colorado Health Sciences Center, Denver, and her colleagues compared the presence of frequent/severe repetitive behaviors and mood/behavioral problems in preschool children diagnosed with an ASD with those of a chronologic-age matched, typically developing control group.

The investigation relied on survey-based ratings by parents or other caregivers of 61 children (mean age 50.5 months) with an ASD who were recruited through the autism research registry at the University of North Carolina at Chapel Hill and 65 children (mean age 46.5 months) with typical development recruited through local preschools and day care centers.

The assessment measures included the Social Communication Questionnaire (SCQ), which screens for the presence of ASDs; the Repetitive Behavior Rating

Scale-Revised (RBS-R), which measures stereotypy, self-injurious behavior, compulsions, rituals/sameness, and restricted interests; and the Nisonger Child Behavior Rating Form (NCBRF), which assesses behavior and emotional problems in children.

The investigators used unpaired t-tests for between-group comparisons of

NCBRF scores for conduct, anxiety, hyperactivity, and overly sensitive behaviors, and Spearman's correlations to determine the relationship within the autism group between mood/behavior problems, autism

symptoms, and repetitive behavior subtypes. Multiple regression analysis determined which NCBRF factor best predicted the total repetitive behavior score.

The data showed that the ASD group had significantly more mood and behavior problems than did the control group. Additionally, within the ASD group, "the RBS-R total score was significantly correlated with all four NCBRF subscales," Dr. Gabriels said.

In contrast, none of the NCBRF subscales correlated significantly with the

SCQ social or communication measures.

The multiple regression analysis of the individual NCBRF subscales relative to the RBS-R total score showed that anxiety was the best predictor of the presence of repetitive behaviors in the ASD group.

"Anxiety symptoms increased significantly with repetitive behaviors in the autistic group, but not in the typically developing group," according to Dr. Gabriels.

This finding suggests that the presence of frequent and severe repetitive behaviors could signal increased anxiety in a child with an ASD, Dr. Gabriels said.

Furthermore, she said, such insight into these associations could help in the clinical assessment and management of patients by improving the accuracy of comorbid psychological diagnoses and ensuring appropriate treatment.

With respect to the anxiety finding, the male:female ratio in the ASD group was 9:1, "so it is possible that the strong relationship between more frequent/severe repetitive behaviors and symptoms of anxiety may reflect the tendency of males to have higher levels of externalizing behaviors than females," Dr. Gabriels pointed out.

Further study is needed to gain more insight into the nature of the association, she said. ■

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