Study Title:
Treatment Patterns in Children with Autism in the United States
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About SPARK Research Match
This SPARK program matches families with research studies they may want to join. These studies have been evaluated for scientific merit and approved by a scientific committee at SPARK. The program is free to researchers and families. SPARK does not endorse or conduct the studies. Families choose if they want to participate in a particular study.

More than 5,000 SPARK participants took part in a study of the treatments — other than medication — that their child with autism received in the past year. The American Academy of Child and Adolescent Psychiatry recommends using more than one type of treatment in autism spectrum disorder (ASD). The study team wanted to learn what types of treatment children ages 3 to 17 received, for how long, and what factors were associated with these treatments.

Study Team
Brigitta U. Monz, MD  
(F. Hoffman-La Roche Ltd.)

Richard Houghton, MSc  
(F. Hoffman-La Roche Ltd. and School CAPHRI, Maastricht University)

Kiely Law, MD  
(Kennedy Krieger Institute, Johns Hopkins University School of Medicine, and mother of an adult with autism)

Georg Loss, PhD  
(F. Hoffman-La Roche Ltd.)

The study, which was funded by F. Hoffmann-La Roche Ltd., was published in Autism Research in January 2019. SPARK does not have any direct relationship with F. Hoffmann-La Roche Ltd.
Almost all children (96%) were receiving at least one treatment, mainly at school. More than 40% were receiving four or more treatments. Here are the most common treatments.¹

1 In the survey, treatments were grouped together and examples of each were provided.

Findings

What treatments are used most often by children with autism from ages 3 to 17?

Almost all children (96%) were receiving at least one treatment, mainly at school. More than 40% were receiving four or more treatments. Here are the most common treatments.¹

- **Speech and Language Therapy**: 71%
- **Other (such as social skills training, academic tutoring, sensory integration)**: 68%
- **Occupational Therapy**: 60%
- **Behavioral (such as Applied Behavior Analysis, Discrete Trial Training, Pivotal Response Treatment)**: 56%
- **Parent-Caregiver Training**: 30%
- **Psychological (such as counseling, Cognitive Behavioral Therapy)**: 29%
- **Developmental/Relationship (such as DIR/Floortime, Relationship Development Intervention)**: 26%
Findings

Do children of different ages receive different treatments?

Yes. Many treatments were used most often with children ages 3 to 4, and less frequently with older children. There were two exceptions: “other” and psychological treatments were used most often with children ages 10-14 and 15-17.
Findings

Is there a relationship between where families live and the treatments their children receive?

Yes. A higher proportion of children in metropolitan areas (large cities and suburbs) received any type of treatment than did children in nonmetro areas (small towns and rural areas). Half the children in metro areas received at least 6 hours per week of therapies, while half the children in nonmetro areas received at least 4.5 hours per week.

**Metro**
Large cities and suburbs

- 96% Any type of therapy
- 57% Behavioral therapy
- 72% Speech-language therapy
- 6 hrs Hours per week of any therapy

**Nonmetro**
Small towns and rural areas

- 94% Any type of therapy
- 46% Behavioral therapy
- 65% Speech-language therapy
- 4.5 hrs Hours per week of any therapy
Findings

What are barriers to treatment, and do they differ based upon where families live?

Almost half of families (45%) reported a barrier to treatment, such as waiting lists for services (26%), cost (17%), or lack of insurance coverage (18%) for a therapy. Some of the barriers related to providers and availability, and how common they were differed according to where families lived. For example, people in metro areas reported more problems with long waiting lists, while people in nonmetro areas were more likely to report that treatments were unavailable.

Is there a relationship between the types of insurance families have and the kinds of therapies their children receive?

No consistent relationships were found between the types of treatments received and whether a child had Medicaid insurance only or private insurance only.
About the Child with ASD

Average Age

9

Gender

80% Boys
20% Girls
About the Child with ASD

Race

- 68% white, not Hispanic
- 16% non-white, not Hispanic
- 6% non-white, Hispanic
- 10% white, Hispanic

Age at ASD Diagnosis

- 26% 0 to 2 years
- 39% 3 to 4 years
- 28% 5 to 9 years
- 7% were older than 9 years
About the Child with ASD

Child’s Mental Health

- 53% Parents report no other mental health or psychiatric problems
- 47% Parents report other mental health or psychiatric problems

Child’s Type of School

- 78% attend general education schools
- 22% attend schools with special education students only
About the Child with ASD

Child’s Health Insurance

- **41%** have only private insurance through an employer.
- **30%** have Medicaid only.
- **19%** have more than one type of insurance.
- **8%** have one other type of coverage.
- **2%** are uninsured or insurance status is unknown.

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About the Caregivers Who Participated

Average Age: 39

Relationship to Child:
- Mothers: 92%
- Fathers: 6%
- Other: 2%
About the Caregivers Who Participated

Relationship Status
Married/living with partner
80%

Education
64%
completed college or higher
About the Caregivers Who Participated

**Occupation**

- 59% work full- or part-time
- 30% are full-time caretakers
- 11% other

**Number of Children with ASD**

- 84% have 1 child with ASD
- 16% have 2 or more children with ASD
About the Caregivers Who Participated

Residence

- **81%** live in metro areas (large cities and suburbs)
- **12%** live in nonmetro areas (small towns and rural areas)
- **7%** Unknown

Geographic Location

- **22%** live in the Midwest
- **16%** live in the Northeast
- **25%** live in the **West** including participants from Alaska and Hawaii
- **37%** live in the **South**
“I wanted to thank you for doing this study. We moved to a different state and we found vastly different therapies and available providers. This is a real problem for families.”

– SPARK participant

How important is this topic to you and your family?

4.8 out of 5

How would you rate your experience participating in this study?

4.9 out of 5