

ORIGINAL RESEARCH LETTER

Characteristics of Service Utilization among Chinese and Korean American Autistic Children

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Autism prevalence among Asian-American children increased 2.7 times faster than among non-Latinx White children over the past decade.¹ Yet, families of Asian-American autistic children often face multilevel barriers as they navigate diagnosis, services, and treatments.² Chinese and Korean communities have the highest percentage of limited English proficiency among East Asians. Our earlier research identified multilevel barriers to autism diagnosis in these groups.³ This paper further describes service utilization patterns and reasons for not accessing services in these two communities.

With guidance from an advisory board (described in Yao et al.),⁴ we conducted a statewide community-based needs assessment focused on autistic Asian American children, approved by the Institutional Review Board of University of Maryland, Baltimore, MD. Eligible participants for the larger study were individuals who 1) lived in the state of Maryland, 2) identified themselves as Asian or Asian Americans, and 3) were caregiver of an autistic child ≤ 18 years. We asked 1) has their child received public (Part C) early intervention (EI), and if yes, how they found out about EI; 2) did their child receive a list of 12 therapeutic and other services, and if not, reasons services were not received from a list of eight reasons: 'do not need', 'not aware of service', 'not eligible', 'not available in the area', 'not in the preferred language', 'on waitlist', 'cost', and 'distance'.

Thirty-three parents of autistic children participated, with the majority being Chinese (67%), mothers (93.9%), married (97%), born outside the US (78.9%), English proficient (81.8%), holding graduate degree (60.6%), earning more than \$100,000 in household income (54.6%), and having lived in the US over 10 years (92.3%). All their autistic children were US-born with nearly three-fourths being male (72.7%) and an average

age of 8.9 years (SD = 0.7). About half of the children (48.5%) had an additional diagnosis besides autism.

Forty percent of the participants reported that their child did not receive EI services, meaning children who likely had early signs of developmental delays missed out on a free service available to all American children. Among those who accessed EI (59.4%), assistance came from health professionals (42.1%), friends/community members (26.3%), or was through the parents' own efforts (31.6%). The high rates of access and assistance from healthcare professionals may be attributed to our sample being disproportionately high-income, insured, and English-proficient, which likely facilitated access to healthcare and EI services. Notably, only about one in three parents said they accessed EI on their own, despite no referral to EI being required, indicating a need for more public information on the availability of free EI services.

We examined service use by age group, given we expected age-related differences, and our findings confirmed this (Figure 1). The most frequently reported service for children from birth to age 5 years and those aged 6 to 12 years was speech therapy (71.4 and 80.0%, respectively), while mental health counseling was the most commonly reported service used by children aged 13 to 18 years. Notably, none of the participants reported using vocational training services.

The most frequently reported reason for not accessing services including physical therapy, occupational therapy, mental health counseling, applied behavior analysis (ABA), assistive technology for communication (ATC), dental care, recreational activity, respite care, and vocational training was that parents indicated their child did not need the service (26.3–65.2%, depending on the service). For the services, a lack of awareness was the second most cited reason (7–28%, depending on the service). The primary reason for not utilizing services including speech therapy,

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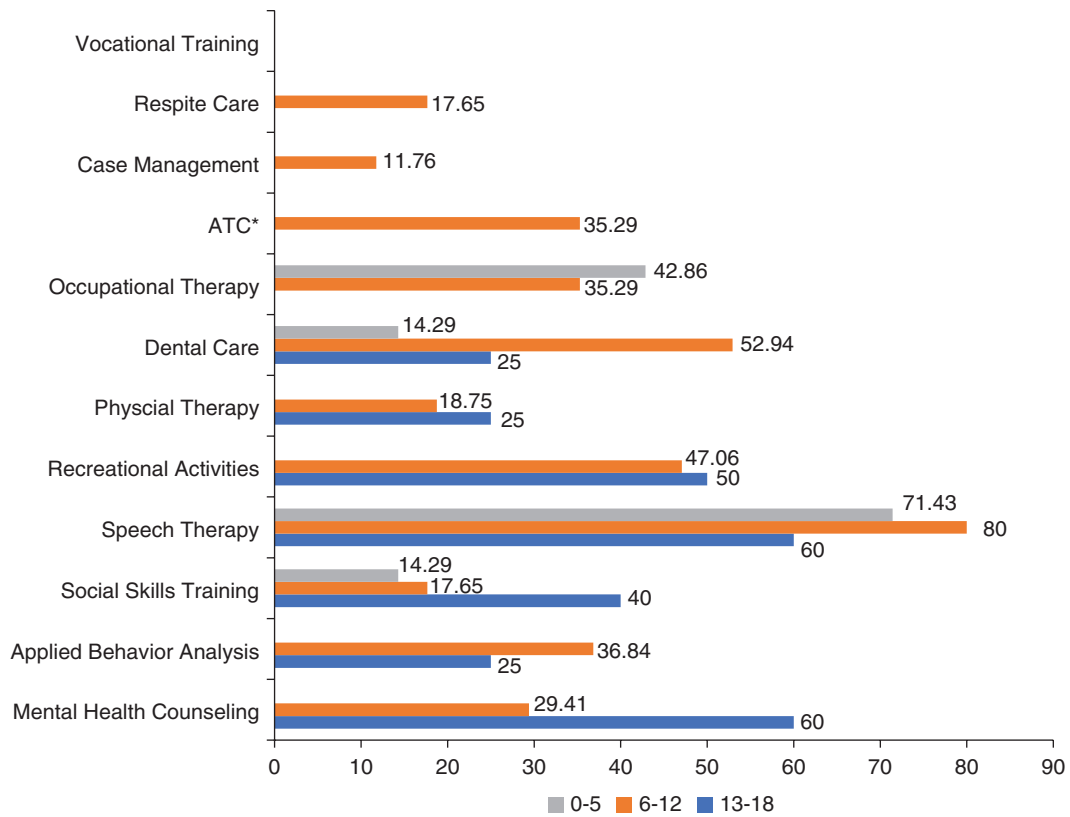


Figure 1. Percentages of services use by child age groups (in years).

Note: We calculated the valid percentages in order to account for missing responses.

*Assistive Technology for Communication.

case management, and social skills training was a lack of awareness of these services (27.3–50%). For ABA, being on a waiting list was also a common reason (7.3%). Additionally, parents cited service cost as a barrier for many services (16.7–23.8% depending on the service), while a few reported ineligibility, unavailability in their area, and distance as reasons for not accessing services. On average, ‘not aware of service’ was the second most frequently reported reason for not accessing services, following ‘do not need’. Given the intersectional identities of our sample of Korean- and Chinese-American parents as racially and linguistically minoritized individuals, they may have faced greater challenges in accessing information about community-based services. This is consistent with findings that under-resourced autistic children received more school-based services than community-based services.⁵

In conclusion, our findings highlight significant barriers to service access for Asian-American autistic children, even those from high-income families. This underscores the urgent need for policymakers to improve outreach and educational initiatives to raise awareness about EI services and other supports. Additionally, further research is needed to explore the unique experiences of racially and linguistically minoritized families, particularly those with low incomes, to ensure that their specific needs are addressed in service delivery and policy development.

Enhancing access to information and services will ultimately support better developmental and familial outcomes.

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