

2021 Gatlinburg Conference Poster Submission

Title: Access to Early Interventions and Services for Families of Children with Autism Spectrum Disorder

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Introduction: Families of children with autism spectrum disorder (ASD) report significant barriers to accessing and engaging in care. Families report delayed or foregone care, difficulty with receiving referrals, care that is not family-centered, and higher rates of unmet service needs relative to other special health populations (Kogan et al., 2008). Difficulties finding and engaging in autism services are exacerbated by the need for specialized care providers, and the difficulty in finding professionals with appropriate training. The majority of prior studies examining service utilization in ASD have simply assessed the number or type of services that a family has successfully accessed over a specific period of time, with the assumption that underutilization reflects problems with access (Krauss et al., 2003). A complimentary way to identify issues of access is to examine the number and type of services initially sought relative to the number and type of services that were successfully accessed and received. Such an approach provides a novel way of understanding the complexity of service seeking and family experience.

Method: An online survey was developed, in partnership with SPARK (Simons Foundation Powering Autism Research and Knowledge) Research Match, to assess the experience of families of young children (18 months to 6 years old) with ASD in seeking and accessing different interventions and services in the community. The newly created survey asked caregivers to report on the number and type of interventions and services that were sought and the number and type of interventions and services that were successfully accessed from a list of 13 possible interventions/services (e.g., behavior therapy or ABA, medication management, occupational therapy, speech therapy). In addition, caregivers reported the number, type, and hours of ASD-related services their child currently receives. Caregivers were also asked to indicate gaps and unmet needs in their child's current intervention programming. Participants (English-speaking primary caregivers of a child with ASD between 18 months and 6 years of age) were recruited through the SPARK Research Match registry.

Results: 324 caregivers of a child between 18 months and 6 years of age (M age = 4.01) diagnosed with ASD completed this survey. Over 58% of families successfully enrolled in sought services. Overall, participants sought between 1.29 to 2.6 different programs per type of intervention/service, successfully enrolling in an average of 1.11 to 1.75 programs per category. Speech and language therapy services were most frequently attempted (by 93.4% of parents), followed by occupational therapy (87.3%) and behavioral therapy or ABA (73.6%). These three categories were also most frequently successfully accessed, as 95.5% of parents who attempted to enroll in speech and language therapy, 92.4% of those who attempted to enroll in occupational therapy, and 72.6% who attempted to enroll in behavior therapy or ABA were successful. Interestingly, families made the most attempts at getting behavioral therapy or ABA services ($M = 2.60$, $SD = 1.91$), followed by speech and language therapy ($M = 2.25$, $SD = 1.42$), and occupational therapy ($M = 1.97$, $SD = 1.38$). The services that were the most difficult to access included nutritional counseling (41.9% of parents who attempted were unsuccessful), followed by mental health counseling (38.9% of those who attempted were unsuccessful), and complimentary or alternative medicine (35% who attempted were unsuccessful). Additionally, parents reported the greatest unmet need in services targeting emotional regulation and anxiety; less than a third of participants who needed support in these areas received it (30.8% for emotional regulation and 28.5% for anxiety).

Discussion: Results from these initial analyses suggest that families of young children most frequently seek out speech therapy, occupational therapy and behavioral therapy or ABA, and that most families are relatively successful in accessing these services. This is promising data as it suggests that many families are able to initiate services, either through the PART C Early Intervention system or elsewhere in the community, that are considered central to a comprehensive early intervention program for young children. Yet, significant unmet needs remain for this population. In particular, these data suggest that underlying mental health challenges such as emotion regulation and anxiety represent an important area of need, and that services addressing these concerns (e.g., mental health counseling) are challenging to access. These findings are consistent with literature from older children with ASD suggesting the need for targeted mental health interventions in this population. Moreover, challenges accessing mental health services in the community suggest that understanding the nature of these difficulties (e.g., lack of providers trained in mental health counseling for young children with ASD vs. financial or insurance barriers to enrolling in services) is critical for developing innovative strategies to ensure timely and appropriate care for young children with ASD.

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