Profound Autism: Uncovering Barriers and Access to Care Among Families

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Objective:
To explore caregiver perceptions of community support, stigma, and service accessibility for children with profound autism, and to identify key challenges affecting care and daily functioning.

Method:
A qualitative focus group approach was used to gather perspectives from caregivers of children with profound autism. Discussions explored experiences with service access, care coordination, and support systems.

Results:
Caregivers reported that although services were often available in principle, they were difficult to access due to long wait times, limited local resources, and challenges integrating care into family routines. Families frequently relied on self-advocacy and independently filled service gaps when formal supports were unavailable or insufficient. Workforce shortage and poor service fit further reduced the effectiveness. Caregivers also described significant emotional, financial, and practical burdens, along with ongoing concerns related to safety and behavioral complexity.

Conclusion:
Caregivers of children with profound autism face substantial barriers to accessing effective and coordinated services. Improving accessibility, strengthening service coordination, and prioritizing family-centered care are critical to better support these families and improve outcomes.