

Autism Initiatives & Resources

Overview: Prevalence estimates of autism have increased over time, reflecting greater awareness, improved screening practices, and increased identification among groups that were historically underdiagnosed. [Current estimates](#) indicate that **1 in 31 children** in the United States are identified as autistic by age 8 years. Autistic children are more likely to have unmet needs for both health care and family support services, higher rates of health care dissatisfaction, and greater family financial strain than children with other special health care needs. Significant barriers exist to families accessing autism services including a lack of knowledge about autism, confusing referral processes, insurance coverage gaps, and lengthy waitlists (months to years) for diagnostic evaluations and intervention services.

Local Initiatives & Resources: Several efforts address these needs locally.

- **DC Autism Collaborative (DC-AC; www.childrensnational.org/dc-ac)**
 - Founded in 2020, the DC-AC is a **multidisciplinary, public-private coalition of professionals and community leaders aiming to strategically address barriers to autism care and advocate for solutions** that will increase early and equitable access to high-quality autism diagnosis, intervention and coordinated care. Importantly, the DC-AC has a [Family Advisory Group](#), led by our partner, the President/Founder of [DC Autism Parents](#), that provides critical input on the work. Through a recent needs assessment, members of the DC-AC highlighted several priorities, including support for service navigation, community education and information-sharing, improved integrated community resources (e.g., DC Parks and Recreation), and enhanced Applied Behavior Analysis (ABA) access and quality.
 - Examples of DC-AC efforts include:
 - Collaborating with OSSE and DHCF to summarize autism prevalence data locally
 - Surveying families about their perceptions of accessibility of the DC Department of Parks and Recreation and the DC Public Library
 - Clarifying guidelines and processes for autism coverage across the DC Medicaid Managed Care Plans to help standardize and improve care for Autistic children (e.g., decreasing regulatory barriers)
 - **Developing many [resources](#) for families, providers, and community leaders**, in addition to serving in an advisory role on issues of autism in the District.

➤ **Community Mental Health (CMH) CORE (Collaboration, Outreach, Research, Equity)**

- The CMH CORE at Children's National Hospital (CNH) works at the **intersection of innovative direct clinical care, policy/advocacy, evaluation, and education, while rooted in engagement with the community**. The CMH CORE serves as the administrative home of the DC Autism Collaborative in addition to leading other efforts to improve autism care locally. Examples of our work include:
 - Published [landscape analyses and policy recommendations](#) on autism care in the District.
 - Lead the CNH Neurodevelopmental Workgroup, which aims to improve coordination of care for Autistic children and those with neurodevelopmental differences at CNH through efforts such as clarifying [referral guidelines](#).
 - Develop and launch innovative gap-filling direct care services, such as the [Autism in Primary Care Program](#), which has increased access to autism evaluations within the CNH community primary care clinics, cutting wait time and age of diagnosis for under-resourced families.

➤ **Building Capacity to Diagnose and Support Autism in the Community**

- The Children's National Center for Autism's **BearACCESS (Building Autism Clinical Competencies through Education and Service Supports) initiative aims to reduce health disparities by addressing the autism care access crisis through provider training and supports**. Targeting frontline providers (e.g., pediatricians and behavioral health providers), is essential as they have routine contact and trusting relationships with autism families.
- The BearACCESS program leverages CNH hospital wide resources and collaborations (HRSA funded LEND program, Pediatric Health Network, philanthropy) and weaves together three evidence-based instructional components to create a multi-modal training initiative that will increase frontline providers' capacity to care for children with autism and thereby, expand access to care. This includes:
 - 1) a triage framework for determining when autism care can appropriately be provided in primary care or another non-specialist setting;
 - 2) a user-friendly provider toolkit for autism diagnostic testing and management of routine autism-related support needs; and
 - 3) a layered mentoring program led by autism specialists involving tele- and direct training opportunities that will support front-line providers as they seek to increase their autism knowledge and confidence and implement autism care in their practice settings. Our goal is to expand the systemic capacity for autism care, thereby reducing bottlenecks at specialist autism centers, and improve access to autism diagnosis and supports for all families.

Conclusions & Recommendations: As the District prepares for a new Mayoral Administration and new DC Council members, it will be important to sustain attention on the growing needs of Autistic children and their families. DC has benefited from strong public-private partnerships that have brought together government agencies, healthcare systems, educators, community organizations, and families to identify gaps and advance solutions. Continued collaboration will be essential to ensuring that Autistic families can access timely, coordinated, and equitable services across systems. Unlike many other populations, autism does not have a single dedicated agency or system owner in the District, which can result in individuals and families being overlooked as they navigate healthcare, education, recreation, and community services. The DC Autism Collaborative and its partners stand ready to serve as a resource to city leaders and policymakers in identifying priorities, informing policy decisions, and advancing efforts that improve outcomes for Autistic individuals.

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