



Charlottesville Region Autism Action Group

Welcome to CRAAG - March 2025

We are so grateful for your interest in CRAAG. We look forward to what you have to offer, and we hope you find what you need. We encourage your engagement in whatever issues concern you at whatever level you see fit. We know joining a group that's been running for a while can be a little confusing, we hope this letter clears things up. We're hoping to recruit more self-advocates and stakeholders to CRAAG's local advocacy team. **Please reach out to CRAAG at craag1@gmail.com if you have any questions or would like to volunteer.**

What is CRAAG's history? CRAAG is a non-partisan, volunteer-run autism advocacy group. Active volunteers are family members of adults with autism or other developmental disabilities (DD), self-advocates and professionals serving our population. Formed in 2010 in collaboration with Commonwealth Autism, CRAAG serves the Region Ten CSB area in Charlottesville City, Albemarle, Greene, Fluvanna, Louisa and Nelson counties. None of the active volunteers are paid, not even our Chairperson or the Steering Committee of 5-8 people.

What is CRAAG's mission? *To raise awareness and enhance the quality of life for people with autism, developmental disabilities (DD), and their families in our region.* Addressing this mission involves focusing on the expansion of community-based housing options and residential supports and services as well as opportunities for meaningful employment, social connections, community engagement and criminal justice reform. We cannot address all these complex problems at once, and we cannot solve them alone.

What does CRAAG do? The following are examples of how CRAAG has advocated for our mission with families, legislators, advocacy partners, providers, and state and local agencies.

- In 2011, we established intermittent public meetings to address state and local issues and to encourage networking with other family members. We launched a newsletter now emailed to 900 subscribers. A webpage and Facebook page came later, in 2016.
- Based on concerns from families, in 2019 we began to research DBHDS's use of the **Supports Intensity Scale—Adult (SIS-A)** as the sole assessment tool to determine a waiver recipients' support needs. The research led us to believe that the support needs algorithm created for DBHDS to calculate the provider reimbursement rates underestimated the needs of adults with autism. We also took issue with DBHDS's failure to offer families an appeal process for the algorithm score and some other aspects of the SIS-A Standard Operating Procedures. We met with representatives of DBHDS and DMAS to discuss our SIS-A concerns. Two CRAAG representatives were invited in 2020 to join the advisory body, SIS Stakeholders Group. We attended public DBHDS advisory sessions on creating the new algorithm and the implementation of the SIS-A Second edition in 2024.
- Surveyed local family members and self-advocates in 2021 to understand their wants and needs with respect to housing options, residential supports and other concerns. In

collaboration with autism researchers of **UVA STAR** (Supporting Transformative Autism Research) CRAAG published two housing reports: ***Housing, Supports, and Service Needs of Adults with Developmental Disabilities: State of Need in Central Virginia*** in 2021 and ***The Housing Needs of People with Autism: Six Case Examples*** in 2023.

- In 2021, we launched three Work Groups targeted to the housing options and residential support needs of different segments of the adult autism population in our area. Our successes:
 - ✓ **24/7 Needs Work Group** encouraged DBHDS to hold a **Supported Living Overview Informational Meeting** in our area for potential and current providers in June 2023. Supported Living is a residential waiver service based in an apartment or home setting that provides 24/7 availability of staff to respond to support needs in a timely manner. Interest was high for this event and several potential service providers attended.
 - ✓ **Maximizing Independence (MI) Work Group** held regular meetings with several local organizations that provide social and recreational opportunities to coordinate activities and improve access for self-advocates across our area. Collaborated since 2022 with the UVA student members of **Autism Allies** to launch a popular social group that meets two Sundays a month during the school year. In 2024 the Work Group collaborated with **UVA STAR, Region Ten, and DBHDS** to hold an invitation-only **Community Assets Mapping** event to gain a better understanding of the existing resources and needs of the community in 2024. Next steps are being worked out. Later in 2025, we hope to launch an online local Resource Guide, a valuable tool for area families.
 - ✓ **Piedmont Virginia Transition Council (PVTC)**, initially named **Planning for Life After High School Work Group**, changed its name and revitalized a region-wide group that faded during the pandemic. It addresses issues related to school-age students (under age 22) who are in transition and facing a drop in resources when they leave High School. The Council meets monthly during the school year and is actively recruiting parents, professionals, and community members to join in learning about and improving transition.
- In 2022, our advocacy efforts toward the General Assembly (GA) ramped up. We were invited to join **The Arc of Virginia's Disability Coalition** to support legislation to benefit anyone with a developmental disability and their families. In 2024 and 2025, we sent delegations to Richmond on **Autism Advocacy Day at the General Assembly (GA)** to meet with our local legislators. This will become an annual event for us. Most significantly, in 2024 CRAAG joined the **Autism Society of Central Virginia, Commonwealth Autism, Decriminalize Developmental Disabilities, and Virginia Autism Project** to co-found the **Virginia Autism Advocacy Alliance (VAAA)**. Subsequently ten other autism advocacy organizations and providers across the commonwealth have joined this informal coalition. VAAA meets regularly to share information and align activities. Increasingly CRAAG sees our local role as complementing the broader efforts of the **VAAA (Virginia Autism Advocacy Alliance)** and **The Arc of Virginia** lobbying efforts.