

## **Welcome to CRAAG (Charlottesville Region Autism Action Group)**

We are so grateful to have you join us. We look forward to what you have to offer, and we hope you find what you need. We know joining a group that's been running for a while can be a little confusing. Don't be shy about asking questions during or after the meeting, but in the meantime, here's a little information on us. At the end of this welcome letter is a list of state and local agencies and acronyms you may hear in our meetings or read in our newsletter.

What is CRAAG's history? CRAAG (Charlottesville Region Autism Action Group) is a parentrun advocacy group. In 2010 in collaboration with CA Human Services (formerly Commonwealth Autism), CRAAG launched as a regional group in the Region Ten CSB area. In the early years, CRAAG established three committees of volunteers – family members of children and adults with autism or other developmental disabilities or providers serving the autism community. The committees worked on adult issues (Lifespan), children's issues (Schools-Children), and outreach (Awareness).

By August of 2018, only the Lifespan Committee maintained enough volunteer participation to be considered active. Recognizing that the core group of supporters were all family members of adults with autism or other developmental disabilities, we stopped identifying ourselves as a committee of CRAAG, dropped the Lifespan terminology, and became CRAAG. Through a group consensus process, we honed our focus on adult services and other over-arching concerns. CRAAG is non-partisan. We set advocacy around adult issues at the state level as one of our highest priorities.

What is CRAAG Today? Our mission is to raise awareness and enhance the quality of life for people with autism, developmental disabilities, and their families in Charlottesville, Albemarle, Greene, Fluvanna, Louisa and Nelson counties. The daily concerns of CRAAG's active volunteers inform our focus on the needs of students transitioning out of high school, adults throughout the lifespan, and their families. Our advocacy is person-centered aimed at maximizing independent living with supports; meaningful employment; social connectivity; and community engagement. CRAAG's 2021 Housing Survey initiated a multiyear project in our region to expand the number of housing options, supports and services available to meet the needs of adults with developmental disabilities.

As a volunteer action group, our supporters are families, self-advocates, and professionals who are interested in all age groups and levels of need. We are well aware that we cannot address all of these problems at once, and that we cannot solve them alone.

Our current efforts focus primarily on helping individuals with autism and other developmental disabilities live away from home and secure employment, if possible. Our meetings address a

combination of state legislative and regulatory concerns as well as local and individual concerns around community based services for adults. CRAAG supporters communicate informally, usually by email, phone, or ZOOM, as needed. We encourage your engagement in whatever issues and at whatever level you see fit.

What about Children's Issues? There has not been sufficient participation to support an ongoing focus on children's issues. But in keeping with the mission of CRAAG as whole and our interest in all age groups and levels of need, we cover children's issues in our newsletter and on Facebook. CRAAG is very open to expanding the mission to focus also on younger children, if a cohort of younger families becomes engaged in CRAAG.

What is the April 2021 Reorganization? CRAAG reorganized to focus on independent living with supports. Through this reorganization we established a Steering Committee and three Work Groups to address the needs of different target groups of adults with autism or other developmental disabilities.

If you are interested in participating in any of these groups, please contact the parent advocate and volunteer named below at <a href="mailto:craag1@gmail.com">craag1@gmail.com</a>. Writing the volunteer's name or the Work Group or Committee name in the email subject line will help us respond appropriately to you.

If you are interested in:

- CRAAG's mission, activities, Steering Committee Bob Kreps (CRAAG's Chairperson)
- Communications/Newsletter Group Susan Jacobson
- Preparing for Life After High School Work Group Maureen Strazzullo
- Maximizing Independence Work Group MaryAnna Dunn
- 24/7 Supports Work Group Greg Hagen

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## Some Common State and Local Agencies and Acronyms Explained

**AA at UVA** *Autism Allies - UVA.* Autism Allies strives to forge connections with local organizations in Charlottesville focusing on community members on the autism spectrum or with related disorders. We seek to make a difference around us by volunteering, fundraising, mentoring, and providing support to these organizations. Autism Allies' mentorship program pairs UVA students with a child or teen who has special needs in our community.

**ADL** Activities of Daily Living. Basic activities such as dressing, meal preparation, accessing public transportation.

**ASD** *Autism Spectrum Disorder.* A developmental disability that can cause significant social, communication and behavioral challenges.

**CSB** Community Service Board. Virginia's point of entry into the publicly-funded system of services for mental health, intellectual disability, substance abuse, and HCBS Medicaid Waivers. Region Ten is our regional CSB.

**CMS** The Centers for Medicare & Medicaid Services. A federal agency that sets rules and regulations for Medicare, Medicaid and HCBS Medicaid Waivers.

**DARS** *Virginia Department of Aging and Rehabilitative Services*. Virginia's employment services, community based services, and other services for people with disabilities.

**DBHDS** *Virginia Department of Behavioral Health & Developmental Services.* Virginia's public mental health, developmental services, and substance abuse services system.

**DMAS** Department of Medical Assistance Services. Virginia's administrative authority for HCBS Medicaid waivers and the agency that submits waiver applications to CMS for approval.

**DOJ Agreement**. Department of Justice Settlement or Agreement. A 2012 landmark federal DOJ finding that Virginia had failed to provide services to individuals with intellectual and developmental disabilities (ID/DD) in the most integrated settings appropriate to their needs. The Agreement binds Virginia to make substantial improvements to serve this population (ongoing).

**FAISON** The Faison Center. The Faison Center's mission is to give children and adults with autism and related challenges the best opportunity to improve their life's journey through evidence-based practice. Our mission across the lifespan is accomplished through specific programs designed to meet the needs of families at different points in their lives: the <u>Faison School</u>, the <u>Faison Behavioral Health Clinic</u>, <u>Faison Adult Services</u>, and the <u>Faison Residence</u>.

**HCBS WAIVERS** *Home and Community-Based Services Waivers*. The HCBS Waivers is a Medicaid program of home and community-based services to meet the needs of people who prefer to get long-term care services and supports in their home or community, rather than in

an institutional setting. They are an essential component of services for high need individuals with ASD, regardless of family income.

**HCBS WAIVER WAIT LIST** *Wait List.* Virginia's Waiver Wait List is years long. Funding for ongoing and additional waivers is appropriated by the Virginia General Assembly (GA) annually. Wait-Listed people are eligible for certain beneficial programs while they wait, so it is important for adults to be screened for the HCBS Waiver early.

**HPR** Health Planning Region. Region 1 DBHDS organizational unit consisting 9 CSBs, including Region Ten CSB.

**ID/DD** Developmental Disabilities refers to a diverse population of individuals with autism, intellectual disabilities, cerebral palsy, and many other life-long developmental conditions.

**JCHC** Joint Commission on Health Care. Virginia GA's standing commission seeks to "ensure that the Commonwealth as provider, financier, and regulator adopts the most cost-effective and efficacious means of delivery of health care services so that the greatest number of Virginians receive quality health care."

**JLARC** *Virginia Joint Legislative Audit and Review Commission*. The Virginia GA's program for evaluation, policy analysis, and oversight of state agencies.

**SSDI** Social Security Disability Insurance Program. Pays monthly benefits to an adult child disabled before the age of 22, if they and/or a parent are "insured," have paid enough Social Security taxes on the earnings.

**SSI** Supplemental Security Income. A means-tested program that provides cash payments to disabled children, adults and individuals aged 65 or older.

**STAR INITIATIVE** Supporting Transformative Autism Research (STAR) at UVA. The STAR initiative, led by the School of Education and Human Development in partnership with colleagues from across the University of Virginia, aims to improve the lives of individuals with autism and their families through ground-breaking interdisciplinary research and development of innovative models for care, support, and education.

**VHDA** *Virginia Housing Development Authority*. A Virginia non-profit that helps Virginians obtain affordable housing.

VIA *Virginia Institute of Autism*. VIA is committed to providing evidence-based services that address the core symptoms of autism. Our programs and services are built around the principles of <u>Applied Behavior Analysis</u>, and employ professionals in the fields of behavior analysis, childhood special education, speech-language therapy, clinical psychology, **and** occupational **and** physical therapies.

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