



Charlottesville Region Autism Action Group

Notes from the October 27, 2021 CRAAG Meeting

Many thanks to the 24 family members, 8 professionals who attended the morning Zoom meeting. The following organizations were represented: CA Human Services, Faison Center, Region Ten CSB, and UVA STAR.

The meeting Agenda

- 1) Review of the discussion with Senator Creigh Deeds (VA-25th District) on October 5th
- 2) Work Group reports
- 3) Announcement of next meeting date/time

Review of October 5th Conversation with Senator Creigh Deeds

Senator Creigh Deeds wanted to hear from CRAAG families to learn about the needs of adults with autism. CRAAG hosted a meeting on October 5th for the Senator. The meeting began with Bob Kreps, CRAAG Chairperson, introducing the issues that most concern CRAAG now. He was followed by Heather Norton, DBHDS Assistant Commissioner. Region Ten's Lisa Beitz and Heather Hines, Executive Director and Senior Director of Adult Developmental Services respectively, spoke next. Senator Deeds was a good listener and very engaged throughout all aspects of the discussion. Senator Deeds' time was very much appreciated by all.

Check out [CRAAG's slides](#) from the October 5th meeting that were presented also at the October 27th meeting.

This is what we heard from CRAAG families and providers at the meeting.

- ✓ The DD system is underfunded and is on the verge of collapse. Transfers from our locality are on the rise as families are having to send their loved ones to other regions, or even leaving the state, to find care or housing due to lack of service providers in our region. Providers are

closing down, and the local staff turnover rate is 72% or higher, leaving many families desperate for residential services, direct service providers and day programs.

- ✓ Higher provider reimbursement rates would be a game changer for many adults with autism who have difficulties accessing services at this time.
- ✓ The waiver slot allocation process is not transparent. Families need clarity about the state's rubric for allocating waivers, since many of the adults with severe autism are not being offered the Community Living Waiver which provides access to 24/7 supported housing options. The process does not seem person-centered.
- ✓ The administrative burden for providers (unreimbursed mandated responsibilities, multiple licensure processes, frequent audits, etc.) is currently being addressed by a committee set up by DMAS and DBHDS. Administrative burden is now recognized at the state level as one of the most important barriers to expanding services to the DD population. Solving it could free up more staff time for direct services.
- ✓ Families also face administrative burdens in trying to establish services and in documenting the needs of their loved ones in order to maintain services.
- ✓ CRAAG has long held that DBHDS needs to study the Supports Intensity Scale (SIS) assessment and the Levels/Tiers algorithm to see how these tools handle the support needs of adults with autism, in particular those with exceptional behavioral and medical concerns. Most of the requests for SIS reassessment (69% in the last year) were triggered by concerns over the way the SIS handles exceptional medical and behavioral concerns. We need answers.
- ✓ The two-tiered rates system that pays providers in Northern Virginia much more than providers in the rest of the state might be reconsidered. There is a growing recognition from legislators that there are other high-cost areas such as Charlottesville/Albemarle, Tidewater and Hampton Roads that need a rate adjustment.
- ✓ Direct advocacy with other families, legislators and agency leaders is the best way to advance our mission to serve individuals with DD and their families. CRAAG will need to decide how to get our message out in the upcoming GA session in January 2022.

Reports from the Work Groups As Of October 27th

24/7 Supports: Greg Hagen (parent) and Matt Osborne (professional – Faison Center in Richmond) lead this group. **Next Zoom Meeting** will be mid to late

November to discuss advocacy efforts concerning waiver rate increases in the next state budget cycle. [Email CRAAG](#) for more information.

Major Obstacle: Lack of service providers (inadequate waiver rates, administrative burden, vague and contradictory regulatory guidance)

Short Term Goals

- ✓ Continue working on financial models for non-waiver related housing expenses (mortgage, rent, utilities, insurance, etc.)
- ✓ Monitor state budget developments related to waiver rate increases
- ✓ Advocate with state legislators concerning the need to significantly increase waiver rates, especially "Supported Living" and "In Home Supports"
- ✓ Resolve regulatory confusion concerning licensing requirements
- ✓ Provide advice to individuals seeking Sponsored Residential and Group Home placements

Mid Term Goal

- ✓ Engage with local service providers to encourage them to provide "Supported Living" and "In Home Supports" in the Region Ten catchment area

Long Term Goal

- ✓ Establish parent/guardian owned/rented residences with 24/7 waiver support available to both CL and FIS waiver recipients

Maximizing Independence Work Group: MaryAnna Dunn (parent) and Amy Berry (professional – Region Ten CSB) lead this group. **The next Zoom meeting will be Wednesday, November 17th from 7 p.m. to 8:30 p.m.** At the October meeting, the group focused on two of the four main goals:

- ✓ **Encouraging Social Groups and Community Engagement:** Two social groups are up and running: a twice-monthly evening bowling activity organized by a group of families and a Sunday afternoon meetup for young adults organized by UVA student group, Autism Allies. The Group is working with the larger community to develop and promote inclusive social activities for more independent adults with autism. A small ad hoc group designed an "interests survey" to identify new interests/activities to promote. [Email CRAAG](#) for more information or to get involved.
- ✓ **Connecting new and existing supporters:** Spent time exploring different ideas for connecting new CRAAG supporters with longer term

supporters. One idea that seemed to resonate with most people, was a regular time for parents to meet up at a coffee shop or restaurant.

- ✓ **New Business:** Heard an update on three living situations: [Osprey Village](#) in Hilton Head, SC, [Renaissance Ridge](#) in nearby Nelson County, VA and [Our Stomping Ground/Gilliam Place](#) in Arlington, VA.

Preparing for Life After High School: Maureen Strazzullo (parent) and Zara Strickler (professional – Region Ten CSB) lead this group. After the November meeting Maureen is stepping down as co-chair of this group. CRAAG hopes to find another parent to co-chair this important outreach group. The leadership of this committee will be on the agenda at the **next Zoom meeting on November 18th from 11 a.m. to 12 p.m.** [Email CRAAG](#) for more information.

The group has made progress on these goals:

- ✓ Completing an efficient [checklist](#) of the most important next steps to guide a young adult through the transition from high school to adulthood.
- ✓ Many thanks to Zara who attended a recent **Special Education Advisory Committee (SEAC)** meeting to share the CRAAG's mission and to inform transition-age parents about our existence.
- ✓ Collaborating and supporting each other and other families who are working through all the steps that will assure a successful transition of their child into adulthood.

Next CRAAG Meeting Date/Time

December 8th from 6:30 – 8:00 p.m. Zoom link will be sent one week in advance

November 15, 2021