February 2018

Good News/Bad News: A Local Perspective on Medicaid Waiver Redesign Phase-In

For this article on the 18 months since phase-in of the redesigned Medicaid waivers, we turned to Region Ten for data and spoke to several families and service providers about their actual experiences. We found good news and bad news.

In September 2016 the Commonwealth of Virginia, in response to deficiencies in its disability support programs identified by the US Department of Justice, began the phase-in of redesigned Medicaid waivers and an expanded menu of services. Out were the old, Intellectual Disability (ID), Developmental Disability (DD), and Day Support (DS) waivers, and in were the 3 new Developmental Disability (DD) waivers theoretically tailored to individual support needs: Building Independence (BI), Family and Individual Support (FIS) and Community Living (CL). This change was long overdue, and families and providers greeted the changes with both anticipation and uncertainty.

- **Good news:** Region Ten is now the single-point-of-entry to access DD waiver services for our area. Families are stepping forward to be screened and qualified. Region Ten’s screening process gets high marks (at least by CRAAG and others). The new menu of services is substantially more expansive than previously available.

- **Bad news:** The lack of available waiver slots shifts roughly half of qualified individuals to a waitlist, portending a looming crisis as the waitlist grows, caregivers age, and natural supports disappear. The lack of qualified autism service providers and residential options stresses the system for families struggling to cope with the needs of their loved ones. Low provider reimbursement rates set by the state and the high cost of living in our area further exacerbate the situation. The lack of truly affordable housing and landlords who accept rental assistance vouchers is another significant barrier.

CRAAG compiled these statistics for Charlottesville, Albemarle, Fluvanna, Greene, Louisa and Nelson:

**Current Waivers for Region Ten Area**

<table>
<thead>
<tr>
<th>Waiver Type*</th>
<th>Currently Served</th>
<th>Post Waiver Reform Slots Awarded</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>FY 2016</td>
<td>FY 2017</td>
</tr>
<tr>
<td>CL</td>
<td>287</td>
<td>11</td>
</tr>
<tr>
<td>FIS</td>
<td>59</td>
<td>5</td>
</tr>
<tr>
<td>BI</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>351</td>
<td>16</td>
</tr>
</tbody>
</table>

* CL - Community Living  
  FIS - Family and Individual Support  
  BI - Building Independence

**Waitlist for Region Ten Area**

<table>
<thead>
<tr>
<th>Current Waitlist</th>
<th>Total**</th>
</tr>
</thead>
<tbody>
<tr>
<td>Priority #1 (services need within 1 yr)</td>
<td>115</td>
</tr>
<tr>
<td>Priority #2 (1 to 5 yrs)</td>
<td>113</td>
</tr>
<tr>
<td>Priority #3 (5 or more yrs)</td>
<td>39</td>
</tr>
<tr>
<td><strong>Total Waitlist</strong></td>
<td><strong>267</strong></td>
</tr>
</tbody>
</table>

**Includes 96 added in 2017**

What the data means for Region Ten:

- 31 new individuals awarded waivers based on their profound and urgent needs, a 9% increase in the number of individuals with waivers
- 96 new individuals added to the waitlist in 2017, a 56% growth in the number of individuals on the waitlist.
- 618 total individuals qualify for waivers: 57% have one, 43% are on the waitlist.
- 115 individuals on the waitlist expected to need services within the coming year, almost 4 times the number who have received waivers since phase-in
Building Independence waivers are expected to be awarded in this fiscal year.

Other observations:

- The menu of waiver services is grouped into 3 versions based on needs. The average annual cost per person varies significantly between the waivers: Building Independence ($24,000), Family and Individual Support ($32,000), and Community Living ($70,000).

- Insufficient funding is the root of the problem. In 2015-2016 Virginia ranked 12th from the bottom in services to individuals with disabilities and 8th from the top among states with the greatest per capita wealth according to United Cerebral Palsy and Pew Research. Virginia can, and must, do better!

- The system is designed to ensure that individuals stay in their families’ care as long as possible. This approach defers the current costs of service delivery and builds risk and hopelessness into the system. “The quickest path to a waiver, is my death” is a common caregiver refrain. “We’ll deal with that when the actual need arises,” the system responds. Caregivers are very worried about deferring these decisions to the future, and they have every right to be.

- Switching between waivers as needs change is part of waiver redesign, however, the process is not seamless or timely. Awarding waivers is a complex evaluative process where hopefully everyone is offered the waiver appropriate to their needs and circumstances. When there is a disconnect between the two, the individual may, through their support coordinator, request a reserve slot to access a different waiver. This list, maintained by DBHDS, is in chronological order by date of referral and not by urgency. Further complicating the issue of switching, at phase-in, the former DD waiver holders (the waiver held by most individuals with autism) were automatically awarded FIS waivers without a case-by-case assessment of whether their needs might be better served by the CL waiver. Families see this as risky and a danger for their loved ones, in particular those with challenging behavioral issues.

We applaud the dedicated agency professionals who are trying to help and for staying the course. They are our allies and share our frustrations. As parents we can have a direct impact by giving voice to the day-to-day realities and the current and looming unmet needs. Twelfth from the bottom is not an option. Being silent and “watching what happens” is not an option. Get involved and make a difference. Join CRAAG.

February CRAAG Meeting

CRAAG Meeting: Mark your calendar now! CRAAG has invited two guest speakers to the next CRAAG meeting on Wednesday February 28th from 10 AM - Noon. The meeting will be held at the Albemarle County Office Building in Room B off the main lobby at 1600 5th Street. Directions and Email.

Speaker: Micah Mazurek, PhD, is a new Associate Professor of Education at UVA’s Curry School. A nationally-recognized expert on autism, Micah Mazurek, moved to Charlottesville in August 2017 to help spearhead UVA’s new autism initiative. She reached out to CRAAG to introduce herself and to explore ways to expand community connections for improving the lives of individuals with ASD and their families. Micah has an active program of federally-funded research focused on understanding and improving outcomes for individuals with autism and their families. Her current research focuses on developing new tools, techniques, and technologies for improving diagnosis, treatment, and access to care for individuals with autism and their families. Micah will talk about UVA’s autism initiative and explore ways to collaborate with CRAAG.

Speaker: Matthew Osborne, M.S., BCBA, LBA, is Director of Adult and Residential Services with The Faison Center for Autism in Richmond. Matthew Osborne's first encounter with autism occurred while he was a college senior supporting a teenager with autism at a public high school. At that time there were very few options in the community for adults with autism. Since then, Matthew has dedicated himself to developing effective, person-centered supports for individuals across the spectrum and across the lifespan. Some CRAAG readers will remember Matthew from when he served as the Director of Adult Services at the Virginia Institute of Autism in Charlottesville and created their Adult Academy. Matthew will share his expertise in residential services, a topic many CRAAG readers consider a top concern.
ADULT SELF-DIRECTED SOCIAL GROUP FORMING: Attention self-advocates ages 18 and older. Are you looking for ways to engage in social, community, and volunteer experiences, but not sure where to begin? Charlottesville Parks and Recreation is convening and providing oversight at first for a group of adults interested in social, community, and volunteer experiences. The first organizational meeting will be on Wednesday, February 7 from 4:30 - 6:00 at C'Ville Coffee. The group will meet on the first and third Wednesdays of the month from 4:30 - 6:00 PM. The first Wednesday of the month is for discussing group goals, objectives and outings. The third Wednesday of the month is for community volunteering or engaging in events. Days and times may vary depending on interests and opportunities. For more information contact Caitlin Marcotte by phone at 970-3269 or by email.

AFFORDABLE HOUSING: Affordable housing advocates will want to attend the City of Charlottesville's 2018 Affordable Housing Summit on Friday, February 16th from 8:30 AM - 4:30 PM at Great Hall, Garrett Building at UVA. Space is limited to 80 people. Register now!

ANNUAL AUTISM CONFERENCE: Registration is open now for Commonwealth Autism's 17th annual Autism Conference, Raising Expectations, on March 7th - 8th in Richmond. Register now!

EXECUTIVE LEADERSHIP TRANSITIONS: Two CRAAG partners have announced executive leadership changes. John Toscano, President and CEO of Commonwealth Autism for the last 16 years, announced his retirement effective June 30, 2018. His successor will be named soon. CRAAG thanks John for his vision for Autism Action Groups and wishes him well in retirement. Following the retirement of Robert Johnson in late 2017, Region Ten welcomed Lisa M. Beitz, LCSW as the new Executive Director on January 15th. Ms. Beitz has 20 years experience working in Virginia's public services system, most recently at the Hanover County CSB. CRAAG welcomes Ms. Beitz and hopes to meet with her sometime soon to share our vision and appreciation for Region Ten's support.

INDEPENDENT HOUSING WEBINARS: Three evening webinars from 7 - 8 PM are planned by the Department of Behavioral Health and Developmental Services (DBHDS). Topics and dates: February 21 - Preparing to Move Into Independent Housing, March 7 - Rental Assistance and Housing Resources, March 21 - Reasonable Accommodation and Modification Requests. Register now!

SAVE THE DATE: The annual Life After High School Transition and Resource Fair sponsored by PREP/Parent Resource Center will be on Saturday, March 17th from 8:30 - 1 PM at PVCC in Charlottesville. Presentations, resource fair, giveaways, door prizes and food. Flyer.

SENSORY-FRIENDLY PERFORMANCE: Accessible Theatre Project and DMR Adventures are partnering to present a sensory-friendly version of Disney's Beauty and the Beast, Jr. on Saturday, February 17th at 3 PM in Charlottesville. Reserve free tickets!

SIBLING SUPPORT PROGRAM: This half-day event on Saturday, March 3rd at Carver Recreation Center is co-sponsored by Virginia Institute of Autism (VIA) and Charlottesville Parks and Recreation. It's designed to provide siblings with opportunities for peer support within a lively, recreational context. More information.

SUMMER 2018 OPPORTUNITY FOR YOUTH: The Youth Leadership Academy is an exciting opportunity for 25 rising high school sophomores, juniors, and seniors with disabilities to hone their career, advocacy, and leadership development skills. Program is held at Virginia State University in Petersburg, VA from July 9-12. Food and lodging paid for by Virginia Board for People with Disabilities! Self-advocates can learn more and apply by March 18th.
Autism Support Groups

CRAAG/BRCCC Special Needs Support Group: for parents and grandparents of children with special needs.

*The venue is changing for February*

**Time:** 2nd Friday of the month from 12:30 - 2:30 PM

**New location:** Panera Bread in Barracks Mall

**More information:** [Flyer](#)

VIA Autism Support Group: Parents/caregivers of a child or grandchild newly diagnosed with autism, join VIA’s Hilary Nagel, MSW, LCSW for support and resource sharing.

**Time:** 1st Wednesday of the month from 9 -10:15 AM

**Location:** C’ville Coffee, 1301 Harris St. Charlottesville

**More information:** [Flyer](#)

Fun On The Spectrum: For parents and youths ages 18 to young adult

**Time:** 2nd Thursday of the month from 7:00 - 9:00 PM

**Location:** Maple Grove Christian Church Youth Center, Profitt Road, Charlottesville

**More information:** [Flyer](#)

Recreational Activities

**ATA Martial Arts for Children with Autism**

For children ages 3+

**Time:** Tuesdays & Thursdays, 3:30 - 4 PM

**Location:** 243 Zan Road, Charlottesville

**Flyer**

**Autism Class at the Little Gym**

For children ages 4 to 10

**Time:** Fridays, 5 - 5:45 PM

**Location:** Stonefield, 2075 Bond St., Suite 140, Charlottesville

**Flyer**

**Therapeutic Recreation**

Charlottesville Parks & Recreation

**Newsletter**

**Special Olympics - Virginia**

Provides year-round sports training and athletic competition in a variety of Olympic-type sports for children and adults with intellectual disabilities.

**Website**

Selective Links for Waivers and Waitlist*

Region Ten is our single-point-of-entry into the DD Medicaid waivers - important documents:

- [Screening Letter](#)
- [Screening Request Form](#)
- [Virginia Individual Developmental Disability Eligibility Survey (VIDES) - Adult Version](#)
- [Virginia Individual Developmental Disability Eligibility Survey (VIDES) - Childrens Version](#)
- [Virginia Individual Developmental Disability Eligibility Survey (VIDES) - Infant Version](#)

Comprehensive [Guide](#) of the DD waiver system
Concise Overview of the DD waiver system

2017 slideshow of the wealthiest states - Virginia ranks 8th from the top - published in US News & World Report based on data from Pew Research

2016 state by state comparison of disability services - Virginia ranks 12th from the bottom published in Case for Inclusion by United Cerebral Palsy

Waitlist individuals may qualify for resources while they wait - requires additional screening

CCC Plus Waiver (formerly the EDCD and Technology Assistive Waivers)

Crisis services - REACH

Community Support Services - Individual and Family Support Program and DBHDS Housing and Flexible Funds

* Links change monthly