

# **Report on the Recommendations of the Virginia Autism Advisory Council 2013**

## **Members**

### **Legislative Members:**

The Honorable Emmett W. Hanger, Jr., Chair  
The Honorable Thomas A. Greason, Vice Chair  
The Honorable Stephen H. Martin  
The Honorable Kenneth R. Plum  
The Honorable Timothy D. Hugo  
The Honorable G. Manoli Loupassi

### **Citizen Members:**

Ms. Jennifer Lassiter  
Mr. Krishna P. Madiraju

### **Staff:**

Ryan Brimmer, Staff Attorney, Division of Legislative Services  
Sarah E.B. Stanton, Staff Attorney, Division of Legislative Services  
Emily Bowles, Senate Committee Operations

### **Website:**

<http://dls.virginia.gov/commissions/aac.htm>

## **BACKGROUND**

The Virginia Autism Advisory Council is the legislative body charged with promoting coordination of services and resources among agencies involved in the delivery of services to Virginians with autism spectrum disorders (ASDs) and increasing public awareness of such services and resources.

Section 30-327 of the Code of Virginia provides that the Commission shall submit to the Governor and the General Assembly progress updates and recommendations by December 1, 2013. The following is a summary of the Council's progress updates and recommendations.

## **PROGRESS UPDATES**

### August 21, 2013 Meeting

The Council held its inaugural meeting on Wednesday, August 21, 2013 in the Third Floor East Conference Room of the General Assembly Building. The members present unanimously elected Senator Hanger as Chair and Delegate Greason as Vice Chair of the Council. After the Council was properly constituted, Sarah Stanton, staff member, provided an overview of the Council's statutory grant of authority and duties. Ryan Brimmer, staff member, provided an overview of legislative efforts relating to autism spectrum disorders (ASDs) over the past four years in the Virginia General Assembly. Of particular note to the Council was Delegate Greason's HB 2467 (Act of Assembly Ch. 876, 2011), which requires health insurers, health care subscription plans, and health maintenance organizations to provide coverage for the diagnosis of autism spectrum disorder (ASD) and treatment for ASD in individuals from age two to six, subject to an annual maximum benefit of \$35,000 of coverage for applied behavior analysis. Dr. Madiraju inquired as to why mandated coverage ends at age 6, and Delegate Greason responded that although some other states have mandated coverage up to age 10, the issue is funding.

In 2008, the General Assembly directed JLARC (HJR 105) to conduct a study to compare services provided to individuals with ASDs in Virginia to services provided in other states, identify best practices and ways to improve delivery of services to Virginians with ASDs, and assess the availability of ASD training for public safety personnel. Nathalie Molliet-Ribet, Senior Division Chief of the Joint Legislative Audit and Review Commission (JLARC), provided the Council with an overview of the resulting 2009 JLARC report, "Assessment of Services for Virginians with Autism Spectrum Disorders." She reported that JLARC found that programs serving Virginians with ASDs tended to be poorly coordinated: there was no coordinating entity prior to July 2009, no centralized and comprehensive source of information about ASDs, and comprehensive case management was not consistently available. JLARC identified the Department of Behavioral Health and Developmental Services (DBHDS) as the agency to evaluate options for improvement moving forward, such as developing a reliable source of information to educate Virginians about ASDs and available services and either training caregivers or expanding case management services. Delegate Greason noted that the societal costs of a child growing up with autism are significant and highlighted the need for intensive early intervention services. Dr. Madiraju pointed out that there is a shortage of developmental diagnostic pediatricians qualified to make a medical diagnosis of ASD and that while children

wait to be diagnosed, precious time to provide early intervention is ticking away. He suggested that all pediatricians could be trained in the diagnosis of ASD. The Council acknowledged that reimbursement would be an issue.

Next, Olivia J. Garland, Ph.D., Deputy Commissioner, DBHDS presented on the agency's implementation of JLARC's recommendations. She reported that DBHDS published an Action Plan in November 2010 which contains 31 recommendations for improving services to individuals with ASDs. Of the 31 recommendations, 10 have been completed, 10 are in process, and 11 are in need of funding to be completed. Ms. Garland highlighted some of those recommendations, including training 50 new individuals as Positive Behavior Support Facilitators (in progress), establishing a statewide public service campaign regarding early detection and screening for autism (received Federal Combating Autism Grant for this purpose), and providing autism awareness training for all public safety personnel (in progress; Commonwealth Autism Service and Department of Criminal Justice). Ms. Garland also spoke about DBHDS's Individual and Family Support Program: families who are assisting family members with intellectual disabilities and developmental disabilities can apply for grants of up to \$3000 to pay for supports, services, and other assistance such as respite care so that families can go on vacation or participate in other social or recreational activities, for example. Last year, 25% of the families served took care of a family member with an ASD. During Ms. Garland's presentation, the Council also received clarification on the credentials necessary to become a Board Certified Behavior Analyst (BCBA): A six-course series, post-Bachelor's degree, and a passing grade on a final exam that results in BCBA certificate.

John Eisenberg, Assistant Superintendent for Special Education and Student Services at the Virginia Department of Education (DOE), presented to the Council on DOE's effort to implement the education-related recommendations in the JLARC report, "Assessment of Services for Virginians with Autism Spectrum Disorders." In the area of Early Intervention, DOE has focused on training, professional development, and parent education. It published two documents, *Guidelines for Educating Students with Autism Spectrum Disorder* and *Models of Best Practice in the Education of Students with Autism Spectrum Disorders*, to improve the provision of Free Appropriate Public Education (FAPE) by school divisions to students with ASDs. DOE has improved Individualized Education Program (IEP) guidance through training and professional development, including webcasts and facilitated online courses. Additionally, DOE has published *Autism Spectrum Disorders and the Transition to Adulthood* (October 2010), developed Project SEARCH programs that specifically target students with ASDs, and developed transition-specific webinars. Finally, DOE has committed to the improvement of service delivery by participating and serving as a leader in the Communities of Learning in Autism (CoLA) and creating the Virginia Applied Behavior Analysis Consortium, an all-virtual program of course work for students at GMU, VCU, ODU, and Lynchburg College.

Finally, Jaime Hoyle, Senior Staff Attorney at the Virginia Joint Commission on Health Care, addressed the Council and notified the membership that she is currently working on a study, at the direction of the General Assembly in SJR 330 (2013), entitled "Needs of Individuals with ASD Transitioning from Secondary Schools." Ms. Hoyle offered to provide the Council with more details once the study is finalized.

## October 21, 2013 Meeting

The Virginia Autism Advisory Council (Council) held its second meeting on Wednesday, October 9, 2013 in the Third Floor East Conference Room of the General Assembly Building. Representatives provided overviews of the following organizations:

### *Virginia Commonwealth University, Autism Center for Excellence (VCU-ACE):*

Dawn Hendricks, Director of Training, and Carol Schall, Director of Technical Assistance, provided the Council with an overview of the Autism Center for Excellence. The presenters emphasized the importance of adhering to the Virginia Department of Education's four-pillared approach to addressing autism spectrum disorders (ASDs)— collaboration, research, training, and technical assistance—and explained some of VCU-ACE's training and technical assistance efforts:

- Training:
  - Virginia Applied Behavior Analysis Consortium: One syllabus and uniform coursework and supervision in Applied Behavior analysis at 4 institutions of higher education in the Commonwealth.
  - Free, not-for-credit training which focuses on webcasts, online seminars, and online instructional courses.
  - Paraprofessionals in Autism Resource and Achievement Project (PARA-Pro): A variety of training initiatives developed in response to HB 325 (2012). Over 3,000 participants to date.
- Technical Assistance:
  - Local:
    - Pilot program of embedded top-down and bottom-up technical assistance, based on a national model called APERS, serving 13 school divisions. The goal is to improve classroom and school practice and increase administrative support. Results with this effort so far include developing a coaching model, increasing the use of evidence-based practices for social communication, literacy, and functional skills, teacher-to-teacher consultation, middle school social skills clubs, high school peer mentoring clubs, and helping address system-wide issues such as identification and eligibility. Applications from school divisions to be part of the second cohort in this pilot program is due on October 15, 2013.
  - Regional:
    - Communities of Learning in Autism (CoLA): meetings in each of the 8 regions in Virginia at least twice a year for autism specialist to participate in a broad range of discussion. There is also a CoLA summer institute. There have been almost 1100 participants to date.
  - State:
    - Develop teacher evaluation system modeled after general education system.
    - Develop 'Guidance and Training to Meet the Communication Needs of Students with ASD.'

- Develop guidance and training for transitioning students with ASDs from one setting to another.

Ms. Hendricks and Ms. Schall also described ways in which VCU-ACE has addressed specific recommendations in the 2009 report of the Joint Legislative Audit and Review Commission, "Assessment of Services for Virginians with Autism Spectrum Disorders:"

- Recommendation #1: Centralized source of educational information.
  - VCU-ACE has an outreach coordinator that has approximately 30 contacts/month from family members and service providers.
  - Online courses, trainings, and workshops for parents of children with ASDs.
- Recommendation #3: Standardized screening, diagnosis, and eligibility.
  - Act Early Committee.
  - Published white paper on screening, diagnosis, and identification.
  - Online screening course for medical personnel.
  - Training in Autism Diagnostic Observation Schedule, the "gold standard" in autism diagnostics.
- Recommendation #6: Guidance for early intervention.
  - Shining Stars Conference.
  - Webcasts for professional development.
- Recommendation #10: Guidelines for transition to adulthood.
  - Develop transition-focused publications, materials, and online resources.
- Recommendation #15: Options for greater independence among adults.
  - Collaboration with VCU Rehabilitation Research and Training Center (RRTC).

Ms. Hendricks and Ms. Schall concluded by pointing to three areas in which there remains significant work to do: a centralized source of information; referral, screening, and diagnosis that is standardized and timely; and improving early intervention services.

#### *Virginia Autism Council (VAC)*

Dawn Hendricks, co-chair, provided the Council with an overview of the Virginia Autism Council. The purpose of the VAC is to gather, synthesize, and distribute knowledge about autism, develop best practice tools, and address gaps in the system. Members include representatives from agencies and entities across the state. VAC endeavors include:

- Creating skill competencies for professionals and paraprofessionals. Developed in 2005 and revised in 2010.
- Developing and delivering trainings, strategies trainings, information for parents with children who just received a diagnosis, and information on transition to adulthood.
- VAC website: Contains a one-stop calendar for trainings across the Commonwealth.
- Higher Education initiatives:
  - Recognizing, marketing, and disseminating information on certificates in autism spectrum disorders and programs in applied behavior analysis.

- Tuition reimbursement up to \$300/course for students taking classes in autism. Ms. Hendricks notified the Council that the tuition reimbursement program ceased in 2011.

### *Commonwealth Autism Service (CAS)*

Jessica Philips, Vice President and COO, and John Toscano, President and CEO, provided the Council with an overview of Commonwealth Autism Service. CAS takes a statewide, systems approach to maximize the quality of life for individuals with ASDs. Initiatives include:

- Providing information and resources for individuals with ASDs.
- An inclusive preschool model that CAS hopes to replicate.
- The Dominion School for Autism.
- Multi-day annual conference in March to highlight current topics related to ASDs.
- Collaboration with state government.
- The Learning Institute
  - Continuing Education for BCBAs.
  - Professional Development.
  - Custom training.
  - BCBA supervision.
- Autism Action groups.
  - State agencies, service providers, school personnel, and members of the community coming together to organize and conduct grassroots advocacy.
- Competent Learner Model:
  - CAS is a regional associate.
  - This model is not autism-specific but is very helpful in this area and places a heavy emphasis on coaching.
- Public safety personnel training.
- Partnership for Capacity Development:
  - Ongoing staff development.
  - Supervision of individuals pursuing certificate in Behavior Analysis.
  - Strong presence in 81 corridor.
- Trans-disciplinary Diagnostic and Assessment Clinics
  - Bring school personnel and other professionals together to resolve differences in opinion over diagnosis and assessment.

CAS staff noted that there really aren't any duplicative or competitive practices between CAS and the other organizations in the Commonwealth. CAS doesn't necessarily measure outcomes; rather, it works at the systems level. While there has been a lot of success in the past few years, there are still gaps and areas for improvement. For example, services could be funded as an entitlement, the state could fund system navigators for students with ASDs, there are no mandated supports for individuals with ASDs at the local levels and CSBs don't provide services for students with autism.

*Virginia Department of Aging and Rehabilitative Services (DARS):*

Joseph Ashley, Assistant Commissioner for Grants and Special Programs, and Richard Kriner, Autism Research Coordinator, provided the Council with an overview of service trends and the activities and programs provided by DARS for individuals with autism spectrum disorders:

- Service trends:
  - Increase in clients with ASDs across all major programs.
  - 17% increase in likelihood of employment and \$1200 annual increase in earnings for individuals with ASDs who participate in Vocational Rehabilitation programs.
    - Almost half received DARS-purchased diagnostic and assessment services.
    - Over one third received Supported Employment (SE) services.
    - Total cost (2013): \$3.1 million. \$4421/individual case.
- Activities and Programs:
  - Present:
    - Participation in Project Search replication study.
    - Piloting Comprehensive Autism service models.
  - Future plans:
    - Positive Behavioral Support Intervention
    - Assistive Technology supports (e.g. handheld technology).
    - Provider with expertise in Autism and VR.
    - Specialty caseloads to support intensive and comprehensive planning.
    - Technical assistance in the central office.
  - Work that remains to be done:
    - Expand DRS case services.
    - Establish 5 ASD specialty caseload positions in DRS.
    - Expand employment supports for up to 200 individuals with autism through the LTESS program (\*Staff reported that the Disability Commission recently sent a recommendation to the Governor to restore LTESS funding to 2007 levels).

November 20, 2013 Meeting

Carol Schall and Jennifer McDonough made a presentation to the Council on behalf of the VCU Rehabilitation Research and Training Center (RRTC) about Project SEARCH, nationally recognized program that provides education and employment training for students with developmental disabilities, helping students with disabilities transition from high school to paid employment. More specifically, the presenters explained some of RRTC's research and findings on the effectiveness of the program.

The Council spent the rest of the meeting discussing a work plan for the 2014 interim and legislative and budget proposals for the 2014 Session of the General Assembly. The Council adopted the following recommendations:

## **RECOMMENDATIONS**

- 1. The Appropriation Act should include an additional \$505,990 in each year of the 2014-2016 biennial budget to restore funding to the Department for Aging and Rehabilitative Services for Long Term Employment Support Services, and should include language providing that additional funding for the Long Term Employment Support Services program provided by the Department shall be used only to support those individuals who are working in supported, competitive employment, as those terms are used in federal law, and receiving at least minimum wage.**

The Department for Aging and Rehabilitative Services' Long Term Employment Support Services program provides support services to individuals with significant disabilities who become employed. Current studies of the costs and financial benefits of the Long Term Employment Support Services program indicate that the Commonwealth receives a return on investment of \$3.50 for every \$1.00 spent to provide services through the program.

The Autism Advisory Council recommends that \$505,990 be provided in each year of the biennium to restore funding for the Long Term Employment Support Services program to assist individuals with severe disabilities with accessing and maintaining employment and that language be included in the appropriation act providing that such additional funding be used solely to provide services to individuals who are working in supported competitive employment and receiving at least minimum wage.

This also comes as a recommendation of the Virginia Disability Commission.

- 2. The Appropriation Act should include \$450,000 in each year of the 2014-2016 biennial budget to fund three new sites for the Project SEARCH program offered by the Department of Education and Department for Aging and Rehabilitative Services in coordination with the Virginia Commonwealth University Research and Rehabilitation Training Center and health systems throughout the Commonwealth.**

Project SEARCH is a nationally recognized program that provides education and employment training for students with developmental disabilities, helping students with disabilities transition from high school to paid employment. Through Project SEARCH, students with a variety of developmental disabilities participate in a one-year, business-led, school-to-work program that takes place entirely in the workplace.

Since 2009, the Department of Education, the Department for Aging and Rehabilitative Services, and Virginia Commonwealth University's Research and Rehabilitation Training Center have partnered with health systems to offer Project SEARCH at various hospitals throughout the state. Students in Project SEARCH participate in a series of three 10-week to 12-week internships with different departments within the hospital. Since the first Project SEARCH site was established in 2009, a number of program graduates have been hired by health systems following completion of their internships.



During the 2012-2013 school year, 13 Project SEARCH programs were available in the Commonwealth. Additional funding would allow for the establishment of three new Project SEARCH sites in hospitals in rural parts of the Commonwealth, expanding the availability of the program to unserved areas.

The Autism Advisory Council recommends that \$450,000 be provided in each year of the biennium to fund the establishment of three new Project SEARCH sites in the Commonwealth.

This also comes as a recommendation of the Virginia Disability Commission.

**3. The sunset provision in Virginia Code § 30-329 should be amended.**

The Council is set to expire on July 1, 2014. *See* Virginia Code § 30-329. The Council recommends extending the sunset provision three years to July 1, 2017.

**4. The chairman should send a letter to the Virginia Board of Medicine requesting that the Board contact all pediatricians regulated by the Board about the existence of the Center for Disease Control's "Autism Case Training: A Developmental-Behavioral Pediatrics Curriculum," the opportunity to receive Continuing Medical Education (CME) credit for this course, and the availability of other autism spectrum disorder diagnostic tools.**