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Members Autism Society of the Greater Capital Region

To: Kevin Smith, Deputy Commissioner
Office of Adult Education and Workforce Development

Debora Brown-Johnson, Assistant Commissioner
Vocational & Educational Services for Adults with Disabilities

Howard Goldsmith, Executive Coordinator
Office of Adult Education and Workforce Development

CC: Angelo Santabarbara, NYS Assemblyman of the 111th District



May 6, 2014

Dear Deputy Commissioner Kevin Smith,

We are submitting this proposal to support our request for policy reform with Acces-VR and current service of autistic consumers. We ask for your assistance in making New York the national model for helping autistic people achieve gainful and meaningful employment before the next fiscal year funding reports are released.

Communication Support is a referral that has never been considered by Acces-VR. This medically-necessary¹ specialized model of support is a proven factor in achieving and maintaining gainful employment for autistic adults². In our proposal, we list the appallingly low employment rates of VR successes with autistic consumers. Our proposal does not ask for additional funding, rather the establishing of an agency standard of Communication Support as a default service for autistic consumers.

The following professionals are in support of this proposal:

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¹ A.8512 Autism Insurance Reform, November 1st, 2011

²Müller E., Fritts K.M., Burton B.A., 2000, <http://www.autistics.org/JVRpaper.htm>

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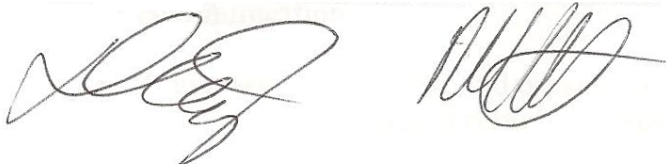
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We thank you for hearing this issue and establishing a line of communication with us. We look forward to meeting with you again and providing more information as needed.

Sincerely,

Henny Kupferstein and Rebecca Botta-Zalucki

Two handwritten signatures in black ink, one on the left and one on the right, positioned below the typed names.

Proposal for Communication Support
ACCES-VR Core Rehabilitation Services (CRS) for Autistic Consumers

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The proposal analyzes how the existing budget for Core Rehabilitation Services (CRS) such as **adjunct** or **790x** referrals can facilitate qualified practitioners to be the recipients of provisions that are the focus of state and federal stewardship of public funds. Specifically private practitioners such as Speech and Language Pathologist and/or Special Education practitioners employed by local vendors already on contract with Acces-VR.

1. Objective

Revising policy for ACCES-VR to incorporate Communication Support as a default Core Rehabilitation Services (CRS) for autistic consumers.

2. Communication Support

Social-pragmatic language differences are inherent in the DSM-5 diagnosis for autism. Current practice recognizes speech therapy as a peer-reviewed effective model for addressing these needs when incorporating the following three components:

- Engaging in dialogue strategies for initiating and exiting communication of intent, and topic maintenance
- Dissolving hostile situations that result from ineffective attempts at independent communication
- Preparing, strategizing, and organizing information for email replies and upcoming interpersonal communication situations

Units: This service is expected to be sufficient with a minimum of three hours per week for at least six months, provided that they occur alongside speech therapy paid by insurance. Without the added insurance-paid service, 1 hour per work-day is estimated to be sufficient (i.e. five hours per week).

Goal: Independent communication skills will actively be learned from these supports so that competence can be achieved for gaining and sustaining meaningful employment.

Explanation: these descriptions may help to solidify what communication support does for the individual:

SC: Social Communication - Development of spontaneous, functional communication, emotional expression and secure and trusting relationships with children and adults.

ER: Emotional Regulation - Development of the ability to maintain a well-regulated emotional state to cope with everyday stress, and to be most available for learning and interacting.

3. History

Federal funding is consolidated to allow for specific referrals made by Acces-VR counselors. The current standards are to refer a consumer to a cluster of services such as Job Placement Services, Job Development with a Job Coach, Supported Employment and Education support. These services are not contingent on specialization of a regulated profession; anybody with a non-specific college degree may apply with the state to be qualified as a vendor.

Autistic people do not benefit from these services alone. Autism is a spectrum disorder which includes many individuals with high education levels and technical skills who have the need for communication support, and not necessarily basic job skills training. Many adults often seek Acces-VR assistance after completing college and/or with savant-level exceptional mastery of specialty area(s) of their strengths. The barriers to employment are communication-based, rather than skill-lacking. Communication support is needed to ensure appropriate job development, employment retention, and skill building that is strength-based. Most people with autism do not enter or maintain employment due to mishaps with communication that lead to termination.

4. Jurisdiction

As is true for autistic adults (and the writers of this report), being referred to the education supports or job developers has caused tremendous grief and distress.

Specifically, these 'specialists' are applying the mental health approach to address communication issues, or administering assessments to determine appropriate job placements without supporting self-determination of the consumer. For example, both writers of this report have been recommended to be placed in janitorial and grocery-bagging positions despite earning college degrees with high honors. These specialists are paid thousands of dollars to assess and report these conclusions to the counselor, which create barriers to meaningful employment and impacting eligibility for appropriate services.

Complaints have been filed with OCR, the district level, the quality assurance department, the office of professions, etc. All have been closed out as unfounded. This is because the counselors are doing their jobs making referrals to the only services allowed by the Commissioner's office, where these policies are determined. The jurisdiction for this issue is at the Deputy Commissioner's office.

Our Calculations (based on *The State Fiscal Year annual reports*):

- 29, 200 Acces-VR annual consumers state-wide
- 4% ASD = 1,168 individuals
- 2.8% with employment outcomes = **32 individuals statewide**
- 88.5% with significant disabilities

5. Medical Necessity

Consistent with the language disorders inherent in the DSM-5 autism diagnosis, we are requesting that Acces-VR recognize Communication Support as a default and viable service for core rehabilitation with autistic consumers. On November 1st, 2011 Governor Cuomo signed A.8512 into law, making New York the 29th state to enact autism insurance reform, ensuring that insurance companies in New York will pay for Speech Therapy for all individuals with an autism spectrum disorder.

6. Acces-VR Statistics

The State Plan for Vocational Rehabilitation Services and Supplement for Supported Employment Services Program Fiscal Reports describes Acces-VR priorities, goals and strategies to involve individuals with disabilities in their pursuit of careers consistent with their strengths, interests, abilities and capabilities. Performance measures are described to assure that Acces-VR services are meeting the standards established in the Rehabilitation Act and that the program is accountable to the public we serve.

The [2014](#) Fiscal Year Funding State Plan, Acces-VR estimates:

- Under Title I and Title VI Part B, approximately [11,000](#) of the estimated 91,000 individuals served during FFY 2014 will receive supported employment services.

- There are 1.05 million individuals 18-64 years of age with disabilities in NYS (8.5 percent prevalence rate).
- In 2009, the percentage of individuals with ASD who achieved an employment outcome (Status 26) was 1.5% of all employment outcomes, representing 183 individuals statewide.

The CDC reports that **1 in 68** have an Autism Spectrum Disorder. For the purpose of demographic sampling, the NYS 111th District Assemblyman Angelo Santabarbara constituents number **93, 950 adults**³. That calculates as **1,382 autistic adults in the Capital Region**, an unserved/underserved Population.

New York State Acces-VR jointly conducted the Comprehensive Statewide Needs Assessment (CSNA) with the State Rehabilitation Council (SRC) for the Federal Fiscal Year (FFY) 2014 to determine the rehabilitation (and other) needs of residents with disabilities and to identify gaps in vocational rehabilitation (VR) services. Key Findings of Population Statistics reveal that **only 4%** of the **29,000 consumers** served by Acces-VR annually are autistic people. Of these numbers, **only 2%** have achieved gainful employment in the last year. The stats are below for reference.

FFY 2012 ACCES-VR Unserved/Underserved Populations⁴

| Disability Group | Total Number (all open and closed) | % of all Active Cases | % of all VR Employment Outcomes | % with Most Significant Disability |
|---|---|------------------------------|--|---|
| Mental Health | 17,392 | 20.2 | 17.8 | 71.5 |
| Intellectual/Developmental Disability (ID/DD) | 14,946 | 19.0 | 18.6 | 78.9 |
| Autism Spectrum Disorder | 2,823 | 4.0 | 2.8 | 88.5 |
| Substance Use Disorders | 16,798 | 17.6 | 20.7 | 39.5 |
| Youth (apply before age 22) | 35,064 | 42.2 | 36.3 | 61.0 |
| SSI/SSDI | 24,606 | 28.9 | 23.8 | 70.9 |
| Visual | 323 | 0.4 | 0.55 | ** |
| Deaf/hard of hearing, deaf/blind | 3,023 | 3.3 | 5.1 | 63.8 |

** ACCES-VR will start reporting this data FFY 2014

The employment gap is an issue of vital concern to the Autism Society of the Capital Region on behalf of their current and potential members who are desperately seeking assistance with gaining employment. Currently, there is a 96% unemployed rate nationally in the autism population⁵.

³ Special Census Bureau tabulations from the 2006-10 5-Year American Community Survey.

⁴ http://www.acces.nysed.gov/vr/adult_vocational_rehabilitation_services/state_plan/attachment_411a.pdf

⁵ There has been some research following employment experiences of young adults graduating from high-school over the last few years but researchers do not know how that reflects the status and experience of older adults. Our data is derived from the U.S. Department of Education National Longitudinal Transition Study-2 (NLTS2), 2009.

Public VR meetings held last year produced the following themes -

- Promote greater engagement of individuals with disabilities in completing Acces-VR services leading to employment,
- Strengthen employment opportunities for these individuals and other suggestions about how to assist individuals to find and keep work.
- Developing strategies to address postsecondary work experiences.

No mention has historically been made to investigate medically appropriate evidence-based services targeted to the nature of the disability as a means to achieving these goals.

7. Traditional Speech Therapy

The following **insurance-based options** are available for speech therapy coverage:

- Medicaid HMO's in New York typically pay for 20 sessions per benefit year, not to exceed a 60-day timeframe.
- Medicaid HMO's in New York can potentially accept an extension but is unlikely.

The issue of speech therapy coverage through insurance should be revisited as all benefits are utilized after 60 days to establish if ongoing communication support will remain sufficient with the units in place at that time.

8. Gainful v. Meaningful

More companies are seeking autistic employees to join their team. Specific patterned-thinkers are highly sought after and handsomely paid for their skill. Theories of motivation can be applied to improve the rate at which they serve individuals with autism. Frederick Herzberg's dual factor theory of motivation specifies that hygiene factors are not motivators (pay, work conditions, the people you work with). Lacking those factors (lower pay) will decrease motivation, but increasing pay will not make a difference. In plain English, "better paid workers are not necessarily happy workers".

Gainfully employed people who are miserable on the job might choose to be penniless and unemployed instead. Rather, motivating factors are employee recognition or honors. Pay does not equal provocation. Conscientious workers will still work hard and do well. Meaningful jobs should be created to motivate workers, and employment should be sought out based on motivating factors. Optimal levels of stress in performance stimulates motivation, an intrinsic arousal of a behavior directed towards a goal.

Theories of motivation remind us that motivation alone is not enough to sustain meaningful employment. The Equity theory states that people look at others in comparison for self esteem needs, and then look to balance the equation of their perception of self. This equation includes effort and performance for an outcome. Value multiplied by performance is going to be the motivator for a valued outcome.

*Performance=function(motivation*ability)* since *motivation=function(v*p)*. When a person is valued for their gifts and strengths and can measure that worth against their colleagues, they in turn are motivated to value the outcome of their productivity.

Per Locke and Latham's Goal Setting Theory, something that is challenging and achievable will be a valuable motivator⁶. The cognitive variables that affect performance is motivation. Autistic consumers most often are not lacking in ability, and they might hold certifications and admirable skillsets that lend to the experience needed to perform. Therefore, the motivation is the variable that is missing to complete the equation. **The motivation must be planned to target the area of need, or it would not be effective.** This motivation strategy would (a) be challenging and achievable because of their history of experience. Then, the consumer would be (b) valued by the validation of the people around them. The consumer would have instant (c) feedback from the interest in their immediate and external environments. The honors and benefits earned would give the consumer more than money can buy.

The validation and feedback can only be effective if communication support is available to analyze, perceive, and process it. The motivation factors rely heavily on social-pragmatic language skills which are unavailable to the untrained autistic consumer. Thus lack of motivation can contribute to feelings of dissatisfaction in meaningless work situations. Gainful employment does not fill the void.

In the News:

- "New, Better Workers on the Autism Spectrum", *Joshua Kendall, Fortune Magazine, July 23, 2013.*
- "How Autism Can Help You Land a Job", *Shirley S. Wang, Wall Street Journal, March 27, 2014.*
- "Startup company succeeds at hiring autistic adults", *Carla K. Johnson, Associated Press, September 22, 2011.*
- "Big Companies Say It's Good Business to Hire People with Autism", *Kristyn Martin, Al Jazeera America, April 2, 2014,*

⁶ Locke, Edwin A., Latham, Gary P., "A Theory of Goal Setting & Task Performance", 1990

- “Tech Company Ramps Up Hiring Of Workers With Autism”, *Michelle Diament, DisabilityScoop.com, April 1, 2014*
- “Tech Giant To Recruit Workers With Autism”, *Michelle Diament, DisabilityScoop.com, May 23, 2013*

Beneficial Traits and Employer Benefits



- **Strong Detail and Process Skills.** Supervisors praise employees with ASD for their accuracy, attention to detail, and skills with complex, repetitive tasks.
- **Increased Diversity.** Integrating people on the autism spectrum into the workplace generates the rewards associated with diversifying the workforce.
- **Dependable, Loyal Employees.** Employees with ASD exhibit character strengths that make them highly desirable employees: focus, reliability, loyalty, honesty, and a preference for work over office politics.

Aspiritech, a nonprofit in Highland Park, Illinois: “Nearly 40% of young adults with autism in the U.S. receive no services whatsoever after high school graduation. “This is an unacceptable situation,” says Brenda Weitzberg, Aspiritech’s executive director. “We are wasting the incredible talents of a growing sector of our population, a group that has important technical skills to offer the business community.”

9. Summary

In order to implement Chapter 143 of the Laws of 2006 and Chapter 484 of the Law of 2008, the Office of Higher Education of the New York State Education Department now requires special education administrators to complete training in the needs of autistic *children*. Furthermore, institutions of higher education must add enhanced coursework or training in autism to their special education programs⁷. The curriculum for these programs must include evidence-based instructional methods/interventions “to support students with ASD in the areas of communication, sensory, social skills and academic learning needs.” The need to continue these supports into *adulthood* is critical to the employability of adults with autism.

⁷ <http://www.highered.nysed.gov/ocue/news/documents/autismsyllabus.pdf>

Proposed Implementations by the Deputy Commissioner:

- Promulgate authorization for VR counselors to refer Communication Support as a default Core Rehabilitation Services (CRS) for Autistic Consumers.
- Require targeted training to CRS practitioners on best practices of working with individuals on the autism spectrum. These practitioners must have a background and/or received training in autism spectrum disorders and **adult** communication need.
- Qualified professionals are individuals who received specialized training in their graduate programs in accordance with the Social-Pragmatic Language Disorders inherent in the DSM-5. These professionals include School Psychologists, Speech and Language Pathologist, Special Education instructors, and CBT practitioners. *The specialized trainings are not true for across-the-board mental health practitioners.*
- Educate employment agencies who are contracted through Acces-VR about the unique needs and challenges experienced by individuals diagnosed with Autism Spectrum Disorders.
- Educate employers about the benefits of hiring individuals diagnosed with Autism Spectrum Disorders.

[END OF PROPOSAL]