



<p><u>Autistic-Led Innovation on Autism Communication Support Programs</u> 5-year Report for 2014-2019</p> <p><i>Quality Assurance and Monitoring (QAM) 2021-2022</i></p>	<p>Prepared for Assemblywoman Wendy Carrillo</p> <p>Henny Kupferstein, Ph.D. Principal Investigator</p>
--	---

Accessible Table of Contents (Clickable)

1. Communication Support	2
Review of the Literature	3
Medical Necessity of Communication Support	4
2. Nationwide Problem	5
Chronology of the Communication Support Programs	5
Underserved Populations	6
ACCES-VR Employment Outcomes: 5-year Review Table	8
3. Demand and Outcomes	9
Flow Chart of Report Data	10
Sister Programs Expansion	11
4. ADA Discrimination by State Programs	12
Case Study of First Recipient	13
Consumer Research Survey	14
5. The A.5141 Bill History	15
Testimony that propelled this legislation	16
Dissolution of Inequitable Programming	19
APPENDIX: Our Organization Mission	21

“If California is to implement an evidence-based service backed by empirical research, the best thing they can do is follow the lead of an autistic Ph.D. researcher.”

- Autistic Colleague

February 8, 2021

This Quality Assurance and Monitoring (QAM) report focuses on 5-year outcomes of the Communication Support program(s) implemented in the State of New York from 2014 through 2019. Our core variables are **gainful and meaningful employment** outcomes in autistic adults and youth, financial self-sufficiency opportunities, and well-being markers. Forming linkages between each piece of legislation (A.5141) and state action adds significant value to the legislative intent of the Autism Action NY package.

The New York legislative fact sheet contains program outcomes. The intention is to underwrite the proposed “**Communication Support**” facilitated by on-call speech therapists in the State of California. In the past 3 years, we have continued to contact state legislators and newly elected officials to make Communication Support a nationwide effort.

1. Most unexpected was the immediate budget provisions for a new transition for youth services that was implemented (Pre-ETS) with Communication Supports.
2. Multiple sister programs ($n=8$) prioritized Communication Supports as defined in the legislation, making benefits and supports accessible through the Independent Living Centers (ILC) funded by ACCES-VR.
3. The NY State Autism Spectrum Disorder Advisory Board (A.8635) who reports to the Governor, is utilizing our legislated model to prioritize interagency awareness and dissemination of Communication Support.



Most notably, disabled consumers in New York remained employed during the **Covid-19 pandemic**. The unemployment rate in New York peaked in [July 2020 at 15.9%](#). Understandably, the pandemic affected millions of individuals with and without disabilities, yet autistic adults who were not in congregate care facilities prevailed. This report highlights a **123% increase in autistic employment rates**. We originally projected a drastic change from 96% unemployment to 85% employed, contingent on Communication Support implementation.

1. In 2014, **only 2.8% of autistic adults** met their ACCES-VR employment outcomes, essentially **32** individuals statewide, which prompted our legislative actions.
2. Based on ACCES-VR 2019-2020 employment outcomes, an estimated **134** autistic adults were reliably employed and fared better during economic hardships than their non-autistic counterparts.¹
3. During COVID19, ACCES-VR employment outcomes peaked at **90.46% without** Employment Support; an antiquated and inappropriate service that was replaced by Communication Support.



¹ We benchmarked our estimates based on the CDC prevalence at 1 in 42, since the State has not reported outcomes by demographic segmentation since our 2014 review.

The outcomes exceeded our employment projections, demonstrating that autistic people who receive **Communication Support**, achieved greater employment outcomes than their disabled peers who continued using **Employment Support & Job Coaching** services. We encourage state agencies who receive [tax incentives for diversity in the workplace](#) to hire *autistic talent*.

Autistics are thriving amidst widespread economic hardships including the current pandemic, because they have a lifetime history of adapting to a changing world, hostile and confusing social settings, and sensory violations. Given the success of the New York pilot program, **Communication Support should be strongly considered nationally, and replicated in California by 2021-2022.**

1. Communication Support boosts job opportunities and assists with maintaining a job once a job is secured.
2. Communication Support is accessible, flexible, and amenable for changing times.
3. Communication Support provided by a Speech Language (SLP) specialist is reimbursable for Telepractice support during shelter-in-place.
4. Communication Support fulfills the ADA by effectively accommodating individuals with a communication disability inherent in an autism diagnosis.
5. Communication Support levels the playing field to accessing meaningful and gainful employment for neurodivergent people.
6. Communication Support facilitates the implementation of affirmative action as autistic adults experience due process.

Once each year, employment outcomes estimates (such as ACCES-VR consumer reports) are revised to reflect updated input data including new programs and demographics (ILC, Transition, etc.). As part of our benchmarking procedures, all state figures are reviewed, calculated for autistic demographics using the CDC prevalence report, and revised as necessary and then re-estimated. We used a time-series regression model to reduce the year-to-year variation in employment outcome rates and sister program consumers served by reducing variation caused by sampling errors and other components of statistical irregularities.

1. Communication Support

We initiated a legislative request in 2014 for New York State. The aim was to implement ADA² mandates for autistic adults to be covered for Communication Support for their communication disability. Additionally, the Communication Support shall be extended to all state and government employees to make accessible the benefits and supports procedures to autistic adults. In our [2014 proposal](#), we defined Communication Support as professional facilitation by speech therapists, per [IDEA](#) definition of this demographic, as an individual who “needs special education and related services” due to “speech or language impairments; autism.”

² Title III Regulation 28 CFR Part 36, Sec. 36.303 Auxiliary aids and services [Auxiliary aid or service necessary to ensure effective communication](#)

Communication Support is a program that utilizes expertise of qualified SLP professionals to deliver the 3 areas of communication support under the ADA, by:

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

2015 A.5141. Legislation Communication Support service definition:

18	<u>(i) initiating and exiting communication of intent;</u>
19	<u>(ii) topic maintenance;</u>
1	<u>(iii) defusing hostile situations that result from ineffective</u>
2	<u>attempts at independent communication;</u>
3	<u>(iv) preparing, strategizing, and organizing information for written</u>
4	<u>or electronic correspondence; and</u>
5	<u>(v) preparing for upcoming interpersonal communication situations.</u>

Review of the Literature

There are supports for autistic children, but there are no covered services for autistic adults. Adults living with autism spectrum disorder (ASD) can experience many factors that may impact their everyday lives. Striving for optimal well being and a meaningful life comes with the ability to access appropriate healthcare services. Yet, [adults with ASD have unmet healthcare needs](#).

The primary aim of our research is identifying the ideal conditions that enable wellbeing for autistic adults.

1. A large majority of autistic adults cannot access resources and supports designated for disabled consumers in the state, because the majority of autistic adults are undiagnosed.
2. Autistic people cannot access a diagnosis due to healthcare disparities.
3. Reportedly, **51%** of ACCES-VR consumers are **white** [FFY 2020](#), p. 20).
4. The covered support available for diagnosed autistics is proven to be ineffective.
5. 96% of autistic people are estimated to be unemployed nationally.
6. The inequity extends from access to job security, financial self sufficiency, and wellbeing throughout the lifespan.
7. Long-term planning is a priority concern for aging autistic adults.
8. A growing (and an increasingly urgent) nationwide discussion among autistics centers on the absence of **gainful** and **meaningful** employment among this population.

Current autism research does not reflect a generalizable discussion among autistic adults as it concerns them. Nicolaidis³ et al., published guidelines for the inclusion of autistic adults in research which indicated that, “effective communication” requires “focus on maximizing autonomy and inclusion, creating an accessible consent process, offering multiple modes of participation, [and] adapting survey instruments for use with autistic adults.” Russell⁴ et al., found that 94% of current autism research collected data from autistics without an intellectual disability, indicating that selection bias leads to “inappropriate generalization” in the findings.

Medical Necessity of Communication Support

Title III Regulation 28 CFR Part 36, Sec. 36.303 [Auxiliary aid or service necessary to ensure effective communication](#) supports must be provided by default without putting the burden on the autistic person to ask for it. These implementations can be witnessed when press conferences provide accessibility captions, translators, and interpreters. The metaphorical ramp or elevator (that autistic adults require to level the playing field) is an equal opportunity to access competitive employment that is a good fit for their skill-sets and strengths. Autistic talent is highly solicited by a select few corporations in Silicon Valley, yet those job opportunities represent a small sample of adults who are skill-abled, but not workforce-ready due to a communication disability.

The [National Center for Education Statistics \(NCES\)](#) is the primary federal entity for collecting and analyzing data related to education in the U.S. and other nations. According to the [NCES Pre-Employment Transition Services](#) report, “Employers value employees who can communicate effectively and act professionally. No matter what technical skills a job may require, every job requires good social skills/interpersonal skills” (p. 19). These skills are often referred to as “Soft Skills.”

Example activities, put forth by [NCES](#), to deliver workplace readiness training aimed at developing social skills and independent living

1. Identify and learn how to use assistive technology in the workplace.
2. Use computer assisted simulation to learn specific job skills.
3. Discuss financial literacy and gaining a general understanding of how benefits may affect working and develop banking and budgeting skills.
4. Simulations to develop social and communication skills.
5. Provide community-based experiences in social skills and independent living skills necessary to prepare for employment.
6. Provide team building experiences to learn how to work as a team or on a team project.

³ Nicolaidis, C., Raymaker, D., Kapp, S. K., Baggs, A., Ashkenazy, E., McDonald, K., ... & Joyce, A. (2019). The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. *Autism*, 23(8), 2007-2019.

⁴ Russell, G., Mandy, W., Elliott, D., White, R., Pittwood, T., & Ford, T. (2019). Selection bias on intellectual ability in autism research: a cross-sectional review and meta-analysis. *Molecular autism*, 10(1), 9. <https://doi.org/10.1186/s13229-019-0260-x>

We recommend to our legislators that we approach this first through the lens of equity. The researchers of this report are passionate because they are part of the autistic community. This writer is yet to receive an employment offer that is amenable to her skills and experience. Due to our extensive legislative work and bill packages, this **program has met and surpassed our projections**, and has succeeded in the **State of New York**. We are pleased to provide this report on efficacy, generated from the existing data.

2. Nationwide Problem

State agencies such as ACCES-VR and the New York State Office for People with Developmental Disabilities (OPWDD), have a mandate for ADA compliance (the [Lanterman Act](#) serves this function in California). Communication impairments are not included in the mandatory training for counselors or service coordinators, and case managers. Further, credentialed autistic faculty are systematically excluded from delivering training and workshops, such as police sensitivity courses.

It is also **outside the scope of practice** for employees in any state to provide Communication Support to a person with a communication disability, as they may not replicate SLP services—a generic service that is defined by each state (i.e. New York State [Office of Professions](#), California Business and Professions Code **BPC § 2530.2**, etc.).

1. Without adequate communication support, autistic people experience the greatest hardship in securing gainful and meaningful employment of any marginalized population in the U.S., including other disabled groups.
2. A credentialed professional is medically necessary to accommodate communication disabilities inherent in all social-communication encounters.
3. The law does not mandate state agencies to defer to licensed communication professionals, creating barriers to accessing eligible benefits on the basis of their autism.

Chronology of the Communication Support Programs

ACCES-VR is the New York State agency that provides adult education and vocational rehabilitation services for disabled adults. Communication Support is a referral that had never been considered by ACCES-VR prior to the introduction of the bill package that resulted from our proposal.

This medically-necessary⁵ specialized model of support is a proven factor in achieving and maintaining gainful employment for autistic adults⁶. In our proposal, we list the low employment outcomes of VR's autistic consumers in 2014, and compare these outcomes over a 5-year span through 2019. Our proposal did not ask for additional funding, but rather stressed the urgency of establishing an agency standard of Communication Support as a default service for autistic consumers per the ADA.

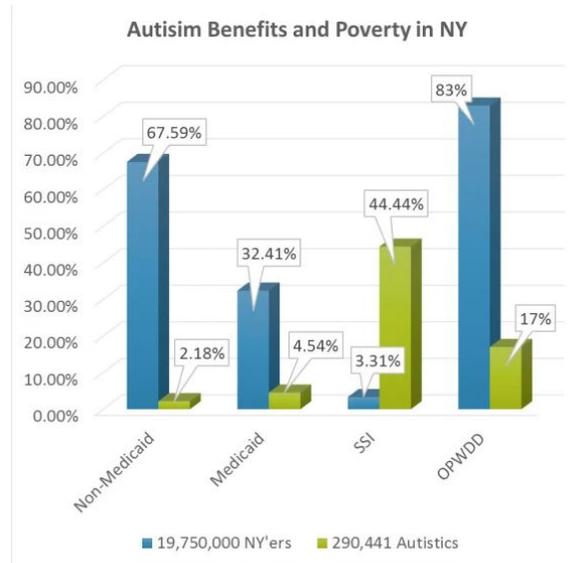
⁵ A.8512 Autism Insurance Reform, November 1st, 2011

⁶Müller E., Fritts K.M., Burton B.A., 2000, <http://www.autastics.org/JVRpaper.htm>

February 8, 2016 - [Autism Action Plan](#)

2016 Proposal prepared for Assemblyman Santabarbara; a five-point plan aimed at increasing job opportunities; providing independent housing options; improving access to information; assisting in communication; and creating a centralized location for services in New York.

February 12, 2015 -Introduced [Bill AO5141 – VR Communication Support for Autistic Consumers](#). A.5141 Directs the commissioner of education to include communication support services as a vocational rehabilitation service.



SOURCE: Botta-Zalucki & Kupferstein, Autism Action NY 2016 Proposal

The lack of reporting by type of support utilized in the employment outcomes, led to a research endeavor to explore these disparities, between our consumer research and agency reports. The employment gap was an issue of vital concern to the Autism Society of the Capital Region (New York) on behalf of their current and potential members who were desperately seeking assistance with accessing meaningful and gainful employment.

Underserved Populations

The ACCES-VR reports differentiated employment outcomes by consumers who were ACCES-VR Funded, or OPWDD Transfers. Their [2012-2013 Report](#) agency performance reports indicated that:

<ul style="list-style-type: none"> a total of 12,025 adults met their employment outcomes, representing 23% of 52,361 consumers served. 	<ul style="list-style-type: none"> An estimated 1,046 autistic consumers experienced a 199.634%⁷ disparity of employment outcomes, comprising only 2% of consumers served. 	<ul style="list-style-type: none"> Comparative to their disabled peers, 2,264 adults and 4,322 youths (4.3% of consumers served) required Employment Support to meet their employment goals.
--	--	---

Underserved and marginalized populations have a history of denial for support required in order to thrive. The New York Governor’s “Employment First” initiative in 2012-2013 proposed by the Executive Order that [sheltered workshops](#) should be developed for conversion plans to transition to employment outcomes of blind and visually-impaired adults. Sheltered workshops consumers mostly earn pennies on the dollar while a support employment worker earns as much as \$42 for that same hour. [There is no reason why we should still follow a standard from the Great Depression.](#)

⁷ According to the CDC, approximately 1 in 11 disabled adults are autistic.

FFY 2012 ACCES-VR Unserved/Underserved Populations⁸

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 of tremendous concern, given that deaf/blind peers had a 2x greater likelihood of meeting their employment goals than autistic adults. In 2014, there was a 96% unemployed rate nationally in the autism population⁹. In 2014, the CDC reported that 1 in 68 have been diagnosed with Autism Spectrum Disorder. For the purpose of scope and magnitude, the demographic sampling of the NYS 111th District Assemblyman Angelo Santabarbara constituents numbered 93,950 adults¹⁰. That calculates as 1,382 autistic adults in the Assemblyman’s district only, and an unserved/underserved population.

- From 2014-2018, CRS Services Report Forms for [ACCES-VR adjunct services](#) did not offer Communication Support or medically-necessary soft skills coaching.

There are an estimated 1 million autistic adults in California equaling that of the 1-million estimated veterans in the State.

February 12th, 2015 - Introduced [Autism Action NY 2016](#) legislative package for the Assembly. The bill package gained the support of the Autism Society, Schenectady ARC, Liberty ARC, GRASP (The Global and Regional Asperger Syndrome Partnership) and New York State Industries for the Disabled, all of whom were represented at the hearing.

1. **The Communication & Technology Bill of Rights** (A.8708) shall include oversight from learning-disabled people to assure ease of access to state and local agency information.
2. **The Home Loan Program** ([A. 8696](#)) shall include the option for autistic adults to obtain a state-funded loan even when on a fixed income. Additionally, a new HOFA grant must be written to bring the monthly costs into the range of a fixed income. The

⁸ http://www.acces.nysed.gov/vr/adult_vocational_rehabilitation_services/state_plan/attachment_411a.pdf, now retired url

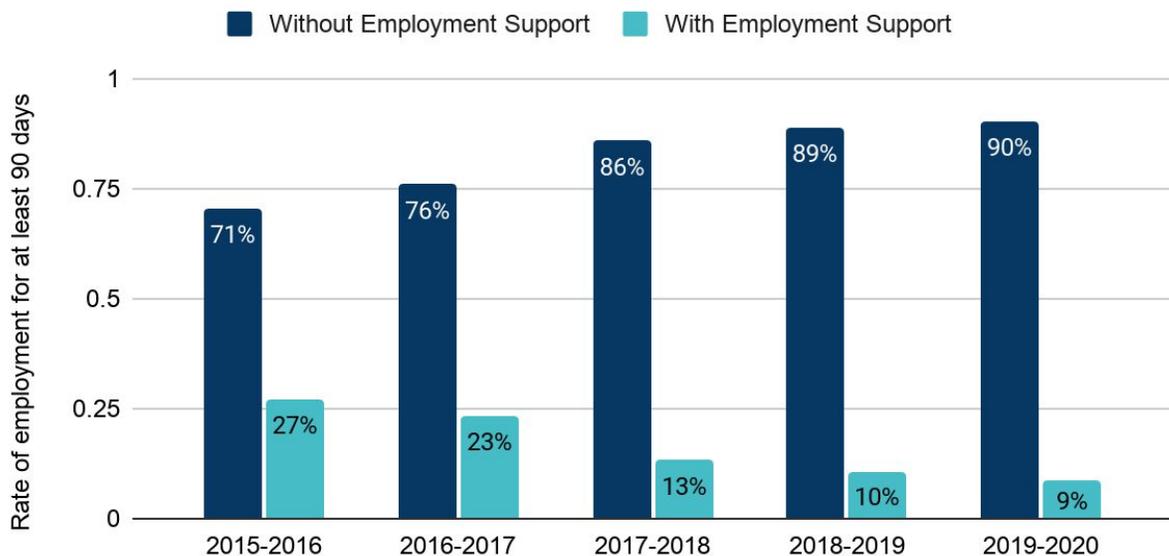
⁹ There has been some research following employment experiences of young adults graduating from high-school over the last few years but researchers do not know how that reflects the status and experience of older adults. Our data is derived from the U.S. Department of Education National Longitudinal Transition Study-2 (NLTS2), 2009.

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

legislation relates to affordable housing for persons with a disability or having attained the age of sixty-two and shall be issued through Independent Living Centers funded by ACCES-VR, to expand the criteria for adults who do not have eligibility for OPWDD, or Mental Health.

3. **The Autism ID Card** ([A00249C/S02565-C](#)) An act to amend the mental hygiene law, in relation to providing for identification cards for individuals with developmental disabilities
4. **The NY State Autism Spectrum Disorder Advisory Board** (A.8635) shall consist of autistic professionals who are credentialed and/or have lived experience to best inform and impact legislation. d to date, receiving both [statewide and national attention](#).
5. **The VR Communication Support for Autistic Autistic Consumers** ([A.5141](#)) Directs the commissioner of education to include communication support services as a vocational rehabilitation service.

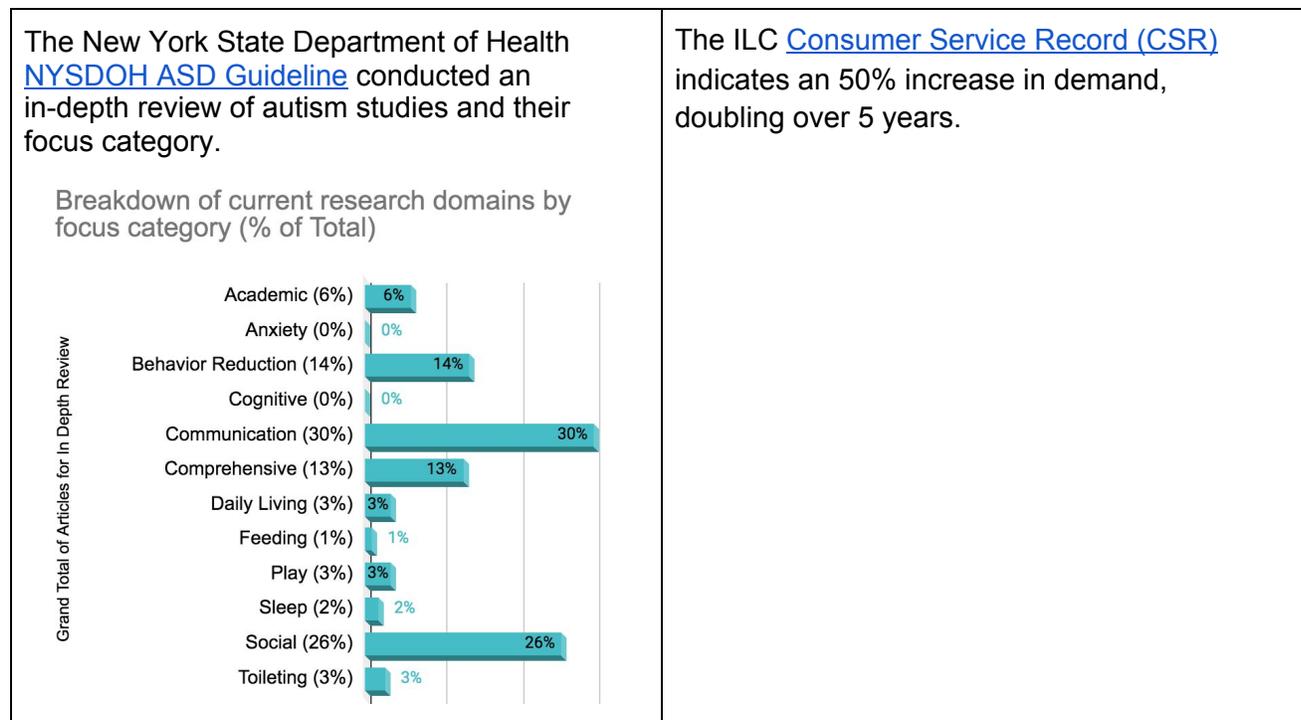
ACCES-VR Employment Outcomes: 5-year Review Table



Outcome Table: This table illustrates that Consumers who achieved their employment goals *without employment support* programs (Navy Bar 1) increased from 70% in 2015 to 90% 2020. Consumers who achieved their employment goals *with employment support* programs (Teal Bar 2) reliability decreased from 27% in 2015 to 9% in 2020. Increase in Communication Support negatively correlates with a decrease of Employment Support programs outcomes that are inappropriate for this population. The data show an inverse relationship between the amount of employment support and communication supports. Based on these findings, ACCES-VR consumers can be expected to continue to meet the same outcomes as their peers, who are increasingly meeting employment goals without employment support. By deduction, this indicates a direct benefit of the Communication Support **sister programs** launched in the state.

3. Demand and Outcomes

1. [ACCES-VR Quality Assurance and Monitoring Unit \(QAMU\)](#) reports unit activities to “exceed[s] the expectations of consumers and federal and state regulations.” The [2013-2019 5-year report](#) does indicate that ILC services have doubled in 5 years.
2. Under the New York State Budget, [ACCES-VR administers](#) base funding for 41 [Independent Living Centers \(ILCS\)](#) throughout the state.



Breakdown of current research domains by focus category: Among the 177 articles reviewed, the 3 most cited domains are Communication (30%), Social (26%), and only 14% on Behavior Reduction, or less than half of Communication priorities in autism research today. Anxiety and Cognitive research studies were at 0% in this report, which indicates that with Communication Supports only, behavior and mental health concerns may be reduced.

The ILC [Consumer Service Record \(CSR\)](#) drastic rise in the total number of individuals receiving assistance, is consistent with the implementation of Communication Support sister programs. In 2017, NYSED ACCES-VR expanded the eligibility criteria by establishing a service rate to meet demand and implementation. The Communication Support adjunct service increased access for the underserved populations from 4% to 9% ([FFY 2020](#), p. 19). Further:

1. Most Significant Disability consumer rates decreased from 80% to 60%. This suggests that Communication Support is a key component that ameliorates the significant impairment.
2. Since implementation, three times as many autistic people are seeking these services, representing dissemination and demand ([Consumer Service Record \(CSR\)](#)).

Flow Chart of Report Data

Table Color Key

Gray = Facts	Teal = Proposal	Red = Legislation	Yellow = Implementation	Orange = Letters of Support	Green = Outcomes	Pink = Sister Programs
--------------	-----------------	-------------------	-------------------------	-----------------------------	------------------	------------------------

2014-2015	2015-2016	2016-2017	2017-2018	2018-2019
<p>2014 <i>ACCES-VR did not offer Communication Support, soft skills coaching; Employment Support programs did not contribute to increased employment outcomes among autistic recipients</i></p>	<p>February 8, 2015 Proposed Autism Action NY plan for 2016</p>	<p>January 14, 2016 Senator David Carlucci Sponsors VR Communication Support for Autistic Consumers. Senate Bill No. S04256 / A05141</p>	<p>January 1, 2017 ACCES-VR Implemented "New Transition Service" for Youth. Prioritizing Social Skills in the Work Setting. Effective Communication. Accepting Supervision. Problem Solving</p>	<p>January 1, 2018 ACCES-VR Implemented 792X-Coaching and Communication Supports as ACCES-VR Adjunct Services</p>
<p>April 25 Proposal for reform submitted to Angelo Santabarbara, NYS Assemblyman of the 111th District</p>	<p>February 12, 2015 Introduced A 5141, which directs the Commissioner of Education to include communication support services as a vocational rehabilitation service.</p>	<p>November 1, 2016 Per Legislation (Mental Hygiene § 13.42), the Autism Spectrum Disorders Advisory Board was established.</p>	<p>New York State - Workforce, Innovation and Opportunity Act 79 VR staff training opportunities for Autism and Related Disabilities: Putting Research into Practice</p>	<p>January 25, 2019 ACCES-VR extended funding for Supported Employment.</p>
<p>May 14 Meeting with Debora Brown-Johnson, Assistant Commissioner of Vocational & Educational Services for Adults with Disabilities</p>	<p>March 10, 2015 American Speech-Language-Hearing Association (ASHA) supports Bill No. A05141 on behalf of speech therapists</p>	<p>December 2016 Nearly 50% of the ACCES-VR caseload consisted of youth age 24 and under</p>	<p>New York State - Workforce, Innovation and Opportunity Act Supported Employment goals and priorities to develop techniques for unserved populations</p>	<p>2018-Present <i>ACCES-VR Core Rehabilitation Services include Communication Support for ACCES-VR transition youth and adults..</i></p>
<p>May 6 Proposal to Kevin Smith, Deputy Commissioner, Office of Adult Education and Workforce Development</p>	<p>May 7, 2015 NYSACRA and NYSRA fully support A 5141 (Santabarbara) and S.4256 (Carlucci)</p>	<p>January 5, 2017 First Responder Training bill introduced (A00249C), passed into law Aug 24, 2018</p>	<p>New York State - Workforce, Innovation and Opportunity Act Added service options that will more specifically address the needs of those on the Autism spectrum.</p>	<p>2014-Present <i>Increase of 8+ sister programs by year</i></p>
<p>June 24 State SRC quarterly meeting members supports proposal during public comment.</p>	<p>May 22, 2015 NYSILC and NYAIL endorse (A 5141, Santabarbara, S. 4256 Carlucci). Communication support in Vocational Rehabilitation Communication Support services</p>	<p>January 26, 2017 ACCES-VR Proposed Workforce Innovation and Opportunity Act (WIOA) Services prioritizing Communication Supports</p>	<p>* Aug 24, 2018 The Autism ID Card (A00249C/S02565-C) signed into law (Ch. 209 of 2018)</p>	<p>2015-Present <i>Employment outcomes for consumers with Employment Support shifted to a 50% increase of ILC Communication Supports.</i></p>
<p>11,272 year-end data Under Title I and Title VI Part B, Employment Support Services extended, communication and social integration supports for an estimated 11,000 consumers.</p>	<p>June 4, 2015 NYSARC, Inc. Memorandum of Support for A 5141/ S. 4256 Autism Communication Support Bill</p>	<p>2018 Advisory Board initial report (2018) prioritized supports to enhance communications to raise awareness and combat discrimination.</p>	<p>2018 <i>Adjunct services now offer Communication Support or medically-necessary soft skills coaching.</i></p>	<p>2014-Present <i>Communication Support programs implemented statewide using the program of Communication Support defined in the legislation.</i></p>
<p>12,025 12,025 (23%) of ACCES-VR Participants overall met their employment outcomes</p>	<p>11,272 Employment Outcomes for ACCES-VR Participants in Integrated Settings</p> <p style="text-align: center; color: purple;">43% Δ difference</p>	<p>10,438 Employment Outcomes for ACCES-VR Participants in Integrated Settings</p> <p style="text-align: center; color: purple;">50% Δ difference</p>	<p>8,962 Employment Outcomes for ACCES-VR Participants in Integrated Settings</p> <p style="text-align: center; color: purple;">74% Δ difference</p>	<p>7,792 Employment Outcomes for ACCES-VR Participants in Integrated Settings</p> <p style="text-align: center; color: purple;">89% Δ difference</p>
<p>13,029 ILC Consumer Service Record (CSR) number of consumers served</p>	<p>17,437 ILC Consumer Service Record (CSR) number of consumers served</p>	<p>17,370 ILC Consumer Service Record (CSR) number of consumers served</p>	<p>19,576 ILC Consumer Service Record (CSR) number of consumers served</p>	<p>20,397 ILC Consumer Service Record (CSR) number of consumers served</p>

Sister Programs Expansion

This section of our report summarizes the progression of implementation of our proposed Communication Support Program and the employment outcomes since their implementation. Each state agency has prioritized a component of our legislated definition of the service, the **3 areas of communication that must be supported under ADA**.

In early 2017, Communication Support was implemented as a covered support for **youth** transitioning into the workplace. The [new transition service](#) was established to meet Workforce Innovation and Opportunity Act (WIOA) requirements for vocational rehabilitation.

- **Pre-Employment Transition Services (Pre-ETS)** prioritized job and career exploration counseling and activities; work-based learning experiences; counseling on postsecondary options; instruction in **self-advocacy**, which may include **peer mentoring**.

[October 1, 2017](#), per legislation (Mental Hygiene § 13.42), **the Autism Spectrum Disorders Advisory Board was established**, prioritizing that “[autistic individuals with appropriate credentials will have a voice when serving the needs of people](#)” (2016, p. 6) by:

- Implementing our peer-support model; a highly effective service delivery model; identifying the funding streams already in place which can be applied to the proposed services and systems of reform.

In 2018, the initial [ASD BOARD report](#) affirmed the ACCES-VR Communication Support as (1) a model for intra-agency communication to establish and endorse Communication Support Program implementation, and (2) **prioritized supports to Enhance Communications to raise awareness and combat discrimination**.

- **Liberty and political feasibility** to bring a Communication Support Program to existing state programs.
- **Efficiency** - captures the process of the Board by reflecting discussions of current State efforts in this area, summarizes public comment and provides a synopsis of the discussions of the self-advocate subcommittee (*resources, results, and how well resources were translated into results*).
- **Sense of Urgency** - greater intra-agency collaboration around general emergency preparedness, to strengthen cross-system communication.
 - The capacity to serve the urgency defined in the legislation materialized as a core outcome of the Board’s report. Essentially, Communication Support was preemptively adaptive to a pandemic.

Today, 2021 - [CRC advertised brochure](#) assures applicants that the agency:

- “assists eligible individuals with disabilities to prepare for, find, and keep suitable employment consistent with their strengths, abilities and interests.”

The 2020 menu of [Core Services](#) for Job Coaching and Employment Supports has shifted to Communication Support ([792x](#)). To date, ACCES-VR effectively outsourced Communication

Support to state funded Independent Living Centers (ILCs). ILC reports indicate a rise in consumer self-sufficiency, employment outcomes, and overall well-being. The consumers with traditional support services were **3x less likely to meet employment outcomes**, signaling the end of an era of antiquated and inappropriate supports.

[The 2019 Board report](#) was composed of a “process” they developed “in a way that reflects the input of those we serve.” The Communication Support Program was implemented by the Board:

1. **Financial efficiency** by utilizing self-advocates to replace costly consumer research
2. **Equity** is prioritized to raise awareness and combat discrimination
3. **Effectiveness**, means that the advisory board’s key priorities for change have been identified, along with actionable solutions to advance them.
4. **Liberty and political feasibility** for “A subcommittee of self-advocates helped shape the recommendations by providing insight from those who have lived experience with autism.
5. Additionally, the Board held **public forums to gain input** from those around the State including many parent participants.

4. ADA Discrimination by State Programs

The conduct of state employees and vendors cannot systematically be criticized nor litigated against because this is a continuing systemic issue. The specifics of the ADA and the specialized skills necessary for facilitating autistic communication recognizes these fundamental flaws:

1. Autistic people who are not entirely economically self-sufficient, have no means of making their own budget, accessing their benefits, or advocating for their support without compromising their self-sufficiency and productivity.
2. The burden that’s been placed on the autistic population is to force effective communication in social settings contingent on job opportunities and financial self-sufficiency, while having a communication disability that’s inherent in autism itself.

“For autistic people, job opportunities and financial self-sufficiency are being made contingent on meeting criteria that are incompatible with autism.” (Kate Gladstone, 2021).

3. The Applied Behavior Analysis (ABA) \$67-trillion industry misappropriated the Autism CARES Act, as evidenced by the presence of similar symptoms in ID/DD recipients of ABA and PTSD Patients ([Kupferstein, 2018](#)). To date, there is no standardized evaluation instrument for PTSD in autistic or intellectually disabled adults and children. As a result, injured autistics are forced to seek support through the CARES Act, which has allotted a frugal \$1.8 million for research for treatment.
4. Statewide insurance denials for speech therapy, on the basis that CMS has regulated medicaid to offer SLP for acquired injuries, ignores these facts:

- a. Autism is a congenital (not acquired) disability — in other words, it is present at birth.
- b. Speech therapy is not a covered cost for autistic adults.
- c. PTSD and Speech/Occupational Therapy are covered costs for an acquired injury in a veteran or stroke patient.

2018: The Board recommends that a targeted communications campaign be developed to be shared with *colleges and *universities offering psychology and related programs.	2019: Prioritized combatting discrimination through *Interagency awareness and communications.	Report to the Governor and the New York State Legislature (May, 2019)
---	--	---

*Completely eliminated is the autistic adult’s lived experience in consumer research reports. Coincidentally, this campaign was also directed toward aspiring clinicians, to be focused on “helping students learn about ABA as an exciting career path.” While many of these campaigns are directed at ABA, there are other equally-successful programs for autistic children and autistic adults. The success of those programs must be considered on their scientific merit before a government report is reviewed for efficacy, because they often miss the mark on thoroughly reviewing both the positive and the negative outcomes of a given procedure or intervention.

We have accomplished this legislation in the [State of New York](#), and are excited that California will soon be the second state to take necessary action to manage this crisis. We are the autistic constituents who are credentialed to serve as policy analysts but who remain under- and unemployed due to lack of access to communication support.

You may recall we projected an increase to an **85% employment rate** within 5 years. The highlight of this 5-year report is that at the 2 ½ year mark of implementation, **43% of autistic adults achieved employment** in the State of New York, drastically reducing the **96% unemployment** rates from 2014. Further research was conducted to allocate these outcomes that resulted from our Communication Support Bill A.5141. To put this in perspective, it is estimated there are as many autistic people in the country and in each state as there are veterans, representing a harsh inequity in terms of service provisions.

Case Study of First Recipient

After the successful passage of the communication support legislation, “Jane” became the first recipient in New York State to receive this service. Jane received more than three months of speech language services from a local, contracted non-profit school. Given that Jane never learned the basics of social communication when she was younger, the speech therapist had to start from scratch.

The ultimate goal was for Jane to maintain the job she had just secured. Before this could be addressed; however, Jane had to learn the basics of social communication. For example, Jane had to learn what constituted an appropriate conversation in the workplace:

- Start with topics such as the weather and the weekend
- Then graduate to more complex conversations on topics such as family and special interests
- learning to maintain an appropriate level of eye contact and not “over-share”

Jane practiced the skills she acquired, learned to be a better self-advocate, and taught her colleagues how to best work with her. This not only helped Jane keep her job, but made her one of the best employees in her department. Jane is still employed at the same agency nearly four years later.

Important to note, when Jane first received "Communication Support" under the new legislation, the speech therapist worked at a school. The therapist wasn't on-call; they met once a week with Jane. Retroactive to [March 1, 2020 during COVID19](#), ASHA (American Speech Hearing Association) rushed to disseminate speech therapy telepractice billing codes to enable online services to continue during shelter-in-place orders. This further demonstrates that the support is portable and equitable to both the provider and the recipient.

Consumer Research Survey

The following 3 questions were submitted to the thousands of agencies, clinicians, and autistic adults who registered in our database for participation in autism research. Further dissemination on social media fulfilled our sample size, while our direct email solicitations saturated our qualitative analysis. The following survey was shared.

(1) When did you experience Communication Support adjunct services connecting adult consumers to this service?

(2) What happened to that individual who was covered for Communication Support?

(3) Did your agency report on the employment rates and self-sufficiency outcomes in the autistic adults who received Communication Support?

A single-blind unsigned email response arrived within 1 business day, from the ACCESSRC <ACCESSRC@nysed.gov>, which is the mailbox for the State Rehabilitation Council (SRC) who advises and supports the State Education Department's Office of Adult Career and Continuing Education Services-Vocational Rehabilitation (ACCES-VR) on behalf of people with disabilities. The SRC wrote that “ACCES-VR's Communication Coaching Supports For Post-Secondary Education and Employment service has been available since January 2019 for any individual with a disability who may need this adjunct service, including students, youth and adults. ACCES-VR serves a wide range of people with disabilities and published reports do not specify types of services that may be provided to specific disability groups.”

5. The A.5141 Bill History

On **May 6, 2014**, we secured a meeting with Angelo Santabarbara, NYS Assemblyman of the 111th District, with the request to listen to our concerns regarding a lack of ACCES-VR and overall employment services for autistic individuals. We discussed the projections made on the proposal, indicating the guaranteed outcomes based on our professional research. The representation of actual autistic credentialed professionals made an impact on the Assemblyman, who disclosed to us that he is the father of an autistic child, whom he described as “severely affected.” We discussed the **New York VR system as we understood it.**

RSA (Rehabilitation Services Administration) is the Federal Education Department governing body for VR agencies nationally. RSA defines what VR is. RSA requires the states to develop their own VR programs. The statuses are defined by the RSA, and the state VR builds its own structures following its own principles.

To have better services, RSA (as a guiding agency) would need to redefine what Communication Support is, and how it should be delivered. Only the largest services are defined by RSA. The services (such as “Supported Employment”) are further named by the state agency. If a service became better defined, it would become mainstreamed into service provision immediately on a state level.

Potentially speaking, VR may put out a request for providers to deliver “Communication Support” through the RFA (Request for Proposal) process. A provider can come forward to offer the delivery of Communication Support using CRS funds already awarded to them for Core Rehabilitation Services (CRS 790x). The provider (agency) ultimately decides how to consolidate their funds to the appropriate practitioner (i.e., Speech Therapist) and how many units they will pay per case. We have identified numerous practitioners who are standing by, waiting to deliver this very specialized service in New York. These are the people who have taken the time to sign our proposal.

As a result of our initial proposal and subsequent legislative actions, the State Department of Education rushed to modify their existing program support options and to implement our program for January 2018. This effort was overtly added to prevent the bill from legislating the vocational rehabilitation division’s programs and services, a mere 10 days before the bill was up for Senate votes. In so doing, ACCES-VR interfered with the legislative and reporting procedures, and they preemptively implemented the proposed Communication Support program of their own volition, with sister programs immediately enacted, all which

generated data that significantly correlates program outcomes with our definition of the service, and matched projection measures from our legislative proposal.

Based on successful legislative activity in the State of New York, this report provides the only comprehensive evaluation of the Communication Support program, and the sister bills we authored. Overall, the proposal projected a 5-year success rate, where the 96% unemployment rates of autistic adults in New York would be *replaced* by 85% employment rates, provided the Communication Support program implemented medically necessary supports and leveled the playing field for both gainful and meaningful employment. **The New York rates of employment have surged past 43% at the 2-year implementation review.**

Stimulating the economy with autistic talent requires a state-level interpretation of the ADA, including accommodation of Communication Support for people with communication disabilities. State agencies are not equipped to be ADA-compliant, due to lack of training by autistic faculty. Police and emergency personnel do not have a statewide standardized requirement for training, or at minimum, the legislated employment opportunity for actual autistic professionals as instructors based on a federal and state combined standard.

Testimony that propelled this legislation

Traditionally, VR job coaching services could be provided by anyone with a high-school diploma. They did not require advanced skills and education. This in-turn, correlated with lower successful job outcomes for disabled consumers. **Educability** and **employability** skills are evaluated for each ACCES-VR applicant, regardless of their employment or education history.

On **March 31, 2014**, this writer had just completed their music therapy undergraduate studies. This writer had received their Bachelor of Science with high honors, and was being recruited by graduate programs. This writer wanted to study psychology, to augment their personal relationship as an autistic adult, situated within the ranks of professionals and stakeholders in the autism field.

This writer's VR counselor made a referral for a "Vocational Evaluation." According to the **Vocational Evaluation Report** (prepared by Ilene Unterman-Zimmer, M.S., Ed, Vocational Services Provider), this writer was Educationally scored to be **profiled** as a demographic who:

"In this range generally have a tendency to complete 7th grade. With regard to training participants who score within this range usually do not benefit from formalized training. Representative job titles for this category include: Packer, Material Handler, Custodian & Janitor, Warehouse Worker, Nurse's Aide and Food Service Worker, among others."

This writer brought this report to share with their peers at the Autism Society-sponsored support group for adults. That is when this writer met new friends, some of whom possessed

highly-skilled, exceptionally technical specific expertise in scientific research toward inclusion and accessibility. We compared our **Vocational Evaluation Report** packets as a group.

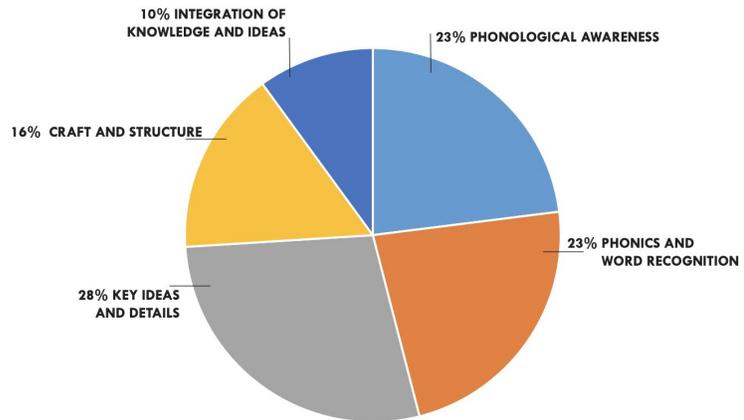
The shock of seeing the identical language for at least two of us was an understatement since at least one of us was completing her Master's degree and was being recruited by government agencies for job opportunities on the basis of her skills — skills that the recruiters attributed to her autism.

Ilene had secured 3 contracts with the State Ed at nearly [\\$2-million dollars](#).

CONTRACT NUMBER	CURRENT CONTRACT AMOUNT	SPENDING TO DATE	CONTRACT START DATE	CONTRACT END DATE	CONTRACT DESCRIPTION	CONTRACT TYPE	FILED DATE
S013688	\$577,523.00	\$90,663.00	01/01/2019	12/31/2023	CORE REHABILITATIVE SERVICES	Grant	12/17/2018
S011289	\$585,231.00	\$384,950.44	01/01/2014	12/31/2018	CONSOLIDATED REHABILITATION SERVICES	Grant	01/27/2014
C009643	\$775,500.00	\$562,271.00	01/01/2009	12/31/2013	UNIFIED CONTRACT SERVICES (UCS) 11000GP003	Grant	03/18/2009

An ACCES-VR vendor rendered a template report that was plagiarized, forged, and that, unethically conned autistic adults into believing their skills to be a sham. The irony of this was that a woman with a master's degree in education became a shoo-in for vendorization with State Ed. The assessment by this vendor was performed on an assessment printed in 1953 (based on the version no. in the footer), but billable to the state in excess of **\$1,800 each**.

The Test of Adult Basic Education (TABE) is a [mandated](#) NYSED-approved test for adult education programs in New York State. The assessment that was administered to this writer (See core [question samples](#)), was based on instrument validity from the early 1920's. A preview of the [core competencies](#) (see *figure at right*) tested by educators are all consistent with a communication impairment inherent in an autism spectrum disorder, and was designed for transitioning youth before adulthood, and not educated adults.



PHONOLOGICAL AWARENESS (23%)	STANDARD	STANDARD DESCRIPTION	AE-CCR LEVEL	TABE 11/12 EMPHASIS LEVEL
	K.RF.2	Demonstrate understanding of spoken words, syllables, and sounds (phonemes). (K.RF.2.a, K.RF.2.b, K.RF.2.c, K.RF.2.d, K.RF.2.e)	A	High

This writer climbed the stairs to a Victorian home with an upstairs shared office above an eye doctor's waiting room. This writer was equipped with a pencil, and was seated at the far end of the cubicle office at a tiny round table. To avoid the glaring light from the window, this writer had to move chairs to situate themselves in an optimal reading position, albeit a documented visual impairment. Then, this writer asked her to please remove the wall-clock and place it in another office for the duration of our time, because this writer was unable to hear themselves speak aloud the written words, and, as a result, their comprehension and speed was diminishing.

When this writer informed the vendor that, due to a visual impairment, they would be unable to track the paper survey to bubble in the responses, she immediately changed her body language and also informed this writer that they must finish the questions independently and without any further requests or complaints.

By 2014, autistic adults in this writer's region were in a conundrum. We had college degrees, yet on paper, appeared to have seventh grade educations and were perceived as not being able to benefit from high-school completion. This is what Vocational Services (VR) was doing to them. This is also what the Department of Rehabilitation (DOR) and Regional Center in California did with this writer. There is an ongoing initiative for Communication Support to be considered a covered default program for autistic adults, regardless of insurance or eligibility for SSI, DDS, or any autism state programs for the developmentally disabled.

Without targeted communication supports, we could not seek affirmative action to endorse the intentional discrimination in previously inclusive places that become un-inclusive when they know that somebody is autistic. When these places are your local food stamps office, or a first responder, the results may end in police brutality or other abuse. These abuses could very well be prevented with standardized training. Our sister bill for **First Responder Training was introduced (A00249C), and passed into law Aug 24, 2018.**

Understanding this writer was not the only one singled out by noncompliant state workers was one benefit of the reward for opening up to the support group. Eventually, we supported each other in connecting to most appropriate supports in the region and online, to become a covered program. The traditional peer support model consistently fails to consider autistic peer supports as part of the generalizable model. Experiences like this writer's made one thing plain to our support group members: This is when we knew: ***We don't break the laws, we write them. We write the laws to benefit others.***

February 2014, we wrote the Communication Support proposal, and waited three months until VR responded to us with a meeting time. We met with Debora Brown-Johnson, Assistant Commissioner of Vocational & Educational Services for Adults with Disabilities. They did not want to keep the printout of the proposal we prepared. We left the building, and one of us met with our VR counselor the same afternoon. The counselor offered one of us a job in janitorial in the State Ed building, the same building we had just left. When Ms. Brown-Johnson heard this, she authorized us to be on the agenda for the next SRC meeting.

We received a meeting invitation and an email to confirm that the proposal would be a handout, and subsequently archived in the minutes. We presented and it went well. They appeared receptive. Kevin Smith, Deputy Commissioner for Office of Adult Education and Workforce Development, requested to shake this writer's hand, thanking them for coming and "educating" NYSED and stakeholders. The next morning, the archived minutes had no mention of the handout; the proposal was buried. It took four weeks of phone calls and emails until Ms. Brown-Johnson called this writer on the phone, and said, "I authorized the handout not to be archived. We cannot publish reports that were not written from within the agency." She assured this writer she put together a committee to investigate the data and the issues we raised.

Without Communication Supports, we were forced to encounter derogatory treatment by Government lawmakers, who as an entity, still functioned with baroque structural and communication concerns. Such self-referential action by a Deputy Commissioner is especially unprofessional, since the proposal specifically quotes her task force which had been established 13 years prior to investigate the underserved populations. Every five years, they published a report that said "More information is needed" about autistic adults in the state. This writer offered to assist the task force, meet with them, and bring the information they are needing. Her response was, "No, the work they do is within." This writer's sources shared that other members brought the proposal up repeatedly in public and private hearings. In the subsequent State meeting, the minutes indicate the question: "What is our response to the autism society public comments?" and the minutes specify that they never heard back from us.

At this juncture, we moved our initiative for program change from state leadership to state legislation.

Dissolution of Inequitable Programming

Gross inequity and misappropriation was resolved by our initiative in favor of consumer benefits. A variety of consumer research projects culminated in the dissolution of inequitable programming in the State, and reclaimed billions of dollars for the State budget.

The Autism ID Card (A00249C/S02565-C) 8/24/2018 Signed into law ([Ch. 209 of 2018](#)). The program was officially launched in the early part of 2019 with nearly 12,000 cards issued to date, receiving both [statewide and national attention](#).

1. NBC New York, Newsday, Autism Spectrum News Magazine and Hamaspik Gazette, highlighted this Act as an important tool to prevent escalations between individuals with disabilities and law enforcement during confrontations.
2. Assemblyman **Nader J. Sayegh (90th district)** introduced [A.8711/S06890](#), an act to amend the vehicle and traffic law in favor of a distinctive mark on an autistic person's driver's license. This bill was [successfully opposed and withdrawn](#) due to violating the legislated Communication Support core components embedded in the task of self identification and self advocacy.
3. **A First Responder Training bill introduced (A00249C), passed into law Aug 24, 2018.** On November 8, 2019, [our letter in opposition](#) to Assembly Member Heastie, Speaker, urged him to oppose the distinctive mark act.

4. **July 1, 2014 - JP's Law Passed in Virginia.** On June 24, 2020, [Pam Mines, autism parent](#) expressed that *“autistic people and/or with intellectual disabilities are not always readily distinguished and are oftentimes misunderstood...because law enforcement was not being trained on this population, how would they know how to recognize that their interaction with this citizen may be different? How would they know how to respond accordingly, or would the citizens’ actions warrant a justified shooting? For all the concern one may have about interactions with the police, imagine when it involves your loved one who is not able to communicate effectively?”*
5. **2020 - Effective Outcome on Inclusion, Equity, and Internationally: Scotland introduced an Autism Alert Card during lockdown,** “allowing autistic people to exercise more frequently if this was important for their wellbeing.” This act effectively ameliorates the potential conflict with law enforcement during high-stress times.

The Home Loan Program (A. 8696) expands the criteria beyond the existing “Home of Your Own” (HOYA) by OPWDD [[url: hence dismantled](#)]. **Central office leadership team, commissioner (518) 473-1997** of [Home of Your Own \(HOYO\) Program](#) confirmed our consumer research that that not a single autistic consumer has benefitted from HOYA, and the sole beneficiaries of the loan program were State employees since its inception more than 20-30 years ago.

1. The HOYA loan was contingent on outcomes of Communication Support, by specifying that individuals are made eligible when they have been employed in a verifiable position for at least three years. This distinction marks the inequity and exclusion of unemployed autistics to purchase a home.
2. Loans that were disseminated inequitably by favoring eligible members of OPWDD’s workforce or voluntary agencies. While the bill was in the Assembly, we referred autistic adults to Mental Health Home loan programs to support equitable distribution.
3. The legislation modified the loan program definition, and co-opted the applications by the Mental Health program instead. Exploitative and predatory practices of misappropriation and inequity of archaic legislation have been replaced with meaningful access to home ownership for disabled consumers in the State of New York. The Bill was referred in 2016 to Housing, Ways and Means, and Rules. Finally, our advocacy shifted the inequity by redefining the eligibility to the home loan program for State employees until they report on consumer outcomes of this program, given their 2016 report does not mention any consumer outcomes. To date, their online presence of the program has been dissolved, but given the lack of reporting, we speculate that they are active through word-of-mouth.

The **Communication & Technology Bill of Rights (A.8708)** shall include oversight from learning-disabled people to assure ease of access to state and local agency information.

1. All state websites hired technology experts and solicited feedback from learning disabled individuals. The state websites were overhauled to display menu of services in multiple formats.
2. A consumer seeking a menu of supports from ACCES-VR may find the forms to request an adjunct service on the state website. Although not entirely accessible, a search

function queries the forms by service code only. “Communication Support” yields no results or directives for obtaining these services.

3. Independent Living Centers have updated their websites and consumers via email to inform them of new services at varying agencies.
4. The online accessibility regulation was part of a disaster planning initiative, which we accomplished, and we witnessed its success during shelter-in-place orders.

APPENDIX: Our Organization Mission

The Doogri Institute conducts research, provides professional training, and directs services through creative and expressive arts to individuals who are disadvantaged both by disability and inequity. Our research and advocacy team consists of scholars and leading experts in their field. All research, professional training, and direct services are augmented by lived experiences. The program creates a bridge for previously oppressed individuals in their quest to immerse themselves in mainstream culture and higher education. This systemic empowerment may lead to self actualization. The Doogri Method includes proprietary wellbeing markers to assure that our work also addresses self image, identity development, and self determination toward actualization, with a specialized focus on [Auxiliary aid or service necessary to ensure effective communication](#).

Dr. Henny Kupferstein is an autistic scientist, specializing in autism research. Her legislative efforts are an extension of her professional research, which blends psychology, autism, and the lived experience of autistic individuals. The [AGP Model \(Kupferstein, 2020\)](#) provides a framework for our organization, through a *de facto* mission for **Inclusion and Equity**.

- Since its inception in 2014, our organizational research identified that we all excel at supporting each other’s communication disability per the ADA, and not spurred by affirmative action. The phenomenon of what we all had psychologically in common spurred the peer support model that eventually became the Communication Support program.
 - The Americans with Disabilities Act (ADA) is a federal law that makes it illegal for employers, state and local governments to discriminate against anyone with a disability; prohibits private businesses from discriminating on the basis of disability, but the ADA neither requires nor prohibits affirmative action.
 - [The California California State Disability Act](#), reiterates that “to qualify for protection, the employee must be able to perform the job’s essential functions.” Our peer support model effectively supports the communication accommodation that correlates with performing the job’s essential function.

[The 2019 Autism CARES Act](#) reauthorized programs and activities that lead to higher-quality services for people with autism. However, Applied Behavior Analysis (ABA) dominated the industry of regulated autism service standards.

- Iatrogenic effects of ABA indicate that it is not a higher-quality service mandated by the Autism CARES Act.
- ABA does not lead to a supported transition for youth.
- ABA severely fails to “[focus] on the health and well-being ... [and] their needs [throughout the life span.](#)”

ABA may severely disrupt the wellbeing of autistic adults who may have been injured during the course of their exposure to inappropriate and ineffective programs of support ([Kupferstein, 2018](#)). Ongoing reports indicate that caregivers quit ABA after they experience concerns when their autistic child is experiencing distressing symptoms similar to PTSD ([Kupferstein, 2019](#)). Lastly, the [TRICARE Comprehensive Autism Care Demonstration Program 2019 report](#) to the Senate for Fiscal Year 2017 is consistent with this second-quarter report for [FY 2019](#), as it reiterates that 76% of TRICARE ABA beneficiaries “had little to no change in symptom presentation over the course of 12 months of applied behavior analysis (ABA) services, with an additional 9 percent demonstrating worsening symptoms.” and resultantly, [TRICARE will no longer cover ABA for veteran families](#), due to the documented **ineffectiveness** of ABA.

<ul style="list-style-type: none"> ● 3.5 million autistics (CDC, 2015) who receive \$45k of ABA per year amounts to \$67-trillion profits to the privatization of Behaviorism. 	<ul style="list-style-type: none"> ● NIMH expenditure for mental in the U.S. rose from \$35.2 billion to \$57.5 billion 1996-2006
--	---

While SSI and IEP plans already segment autism spectrum disorders per the DSM-5, autistics at large are desperately seeking alternatives with proven positive outcomes.

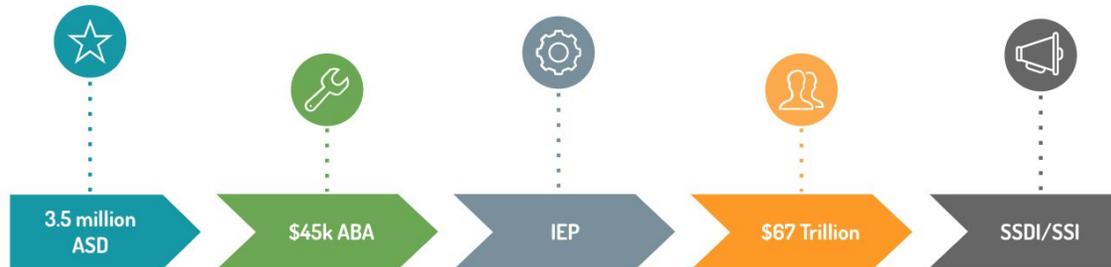
While there has been an influx of efforts to rebrand ABA, we remain committed to the dissemination of documented long-term harm to autistics adults from childhood intervention treatments.

- Applied Behavior Analysis (ABA) is the most prevalent early childhood intervention recommended by clinicians after a child receives a diagnosis of autism¹¹.
- Behaviorists conceptualize autism as a disorder characterized by both behavioral deficits in communication and social skills, as well as excesses such as ritualistic behavior and tantrums¹².

¹¹ CDC (2015) Autism Spectrum Disorder (ASD): Treatment. *Center for Disease Control and Prevention*. Atlanta, GA. March 10, 2017; www.cdc.gov/ncbddd/autism/treatment.html. Accessed May 13, 2017.

¹² Green, G. (1996). Early behavioral intervention for autism: What does research tell us? In C. Maurice, G. Green, & S. C. Luce (Eds.), *Behavioral intervention for young children with autism: A manual for parents and professionals* (pp. 29-44). Austin, TX: PRO-ED.

ANALYSIS



Autism Standards of Care Graphic: This graphic illustrates that if half of the 7 million autistic people in the United States would receive the maximum benefit from covered ABA services, the intense 1:1, 40-hour program would be reimbursable for up to **\$45,000¹¹ per year**, per individual. Medicalized autism is spurring a **\$67-trillion** annual business privatized by behaviorists. Us adults, our autistic children, and the children of the world are entitled by law to experience a non injurious society where they can thrive. [source: “Evidence of Similar Symptoms in ABA Recipients and PTSD Patients”, Kupferstein, H., Presenter, Northern California Autism Symposium, California State University at Chico - September 29, 2017]

Self-Referential Loop of ADA Infringements

Performing the job’s essential function requires a Communication Support initiative to accommodate autistic people who have a medical necessity for communication alternatives that are neither behavioral nor ABA-oriented. Chaos theory teaches us that without control, we need nothing from foresight¹². Yet this loop between federal and state leadership is pure chaos. For example, affirmative action triggers the establishment of the [ADA coordinator](#). The coordinator’s legal job description is yet to be defined, as the result of our surveys indicated:

1. ADA coordination is an unstandardized profession.
2. 81% of the coordinators surveyed in 26 states were not psychologists who can interpret medical reports, but were in fact MBA’s.
3. Autistic adults are ineffective at self-advocacy and protection when asking for help, such that their communication disability impedes their own due process.

We are overtly aware that the inequality begins when an MBA is tasked with minimizing accommodation expenditures contingent on their own job security. To position our efforts as

¹¹ Regulations by State <https://www.ncsl.org/research/health/autism-and-insurance-coverage-state-laws.aspx>

¹² Spears, L. C., & Lawrence, M. (Eds.). (2016). *Practicing servant-leadership: Succeeding through trust, bravery, and forgiveness*. John Wiley & Sons.

innovators, we must model how Communication Support made this report possible to produce, because autistic people are unfairly held to higher standards of functioning and communication than our own government.

Our organization Quality and Assurance Monitoring (QAM) program **generates quarterly reports** from our consumer resource data sources. We innovated as scientists to generate data for our research team to make accessible the process of researching these highly sensitive findings from state reports, with casual admissions to culpability and failures on the part of the highest-spending state agencies. This organizational strategy was designed by a neurodiverse team of autism experts who put the [AGP Model](#)¹³ from theory and into practice, to ensure the employment opportunities of the very people who engage in this field of activity.

- The organization is thriving from the autistic work ethic, which is nourished by the zealous team accommodation and inclusion in our research agenda, in the way we generate jobs, and by creating a consumer research database for transparent reporting, hence forthright, or “Doogri” in modern Hebrew.
- Throughout the non-profit’s lifespan and beyond, our Quality Assurance and Monitoring (QAM) reports prioritize putting into action the ameliorations of our inequity.
- Autistic professionals work as communication supports for each other under our Peer Mentorship model. This is in line with the peer support model that we originally discussed in our 2014 proposal.
- Peer support is an evidence-based method. This innovation has changed the course of each individual’s career and economic self-sufficiency outcomes.
- Innovate by liberating the inequity of traditions of dissemination of scientific research
- Our professional collaborations have launched a revolutionary genre of legislation through 2030; proposed by autistic professionals who bring scientific research to policy discussions and analyses.

Our evidence-based programs are innovative and practical, such that they provide job opportunities for autistic researchers, and have been designed to:

- Self-generate data on efficacy
- Provides a 5-year projection
- Focus on establishing state and federal standards for frontline workers (Police Departments, First Responders, state employees, etc.)
- Maintain a legally-binding, evidence-based process that is informed by the sum total of autistic culture and lived experience.

WHO ARE WE? Our research agenda is to generate a database of medical autism research for comparison of new research on neurodiversity culture. Our demographics are autistic adults who experienced marginalization and oppression because they are disadvantaged by the nature of their communication style. Please allow us to help you care about and understand us.

¹³ Kupferstein, H. (2020) Able Grounded Phenomenology (AGP): Toward an Ethical and Humane Model for Non-Autistic Researchers Conducting Autism Research. (Doctoral Dissertation, Saybrook University: [ProQuest](#)).

innovators, we must model how Communication Support made this report possible to produce, because autistic people are unfairly held to higher standards of functioning and communication than our own government.

Our organization Quality and Assurance Monitoring (QAM) program **generates quarterly reports** from our consumer resource data sources. We innovated as scientists to generate data for our research team to make accessible the process of researching these highly sensitive findings from state reports, with casual admissions to culpability and failures on the part of the highest-spending state agencies. This organizational strategy was designed by a neurodiverse team of autism experts who put the [AGP Model](#)¹³ from theory and into practice, to ensure the employment opportunities of the very people who engage in this field of activity.

- The organization is thriving from the autistic work ethic, which is nourished by the zealous team accommodation and inclusion in our research agenda, in the way we generate jobs, and by creating a consumer research database for transparent reporting, hence forthright, or “Doogri” in modern Hebrew.
- Throughout the non-profit’s lifespan and beyond, our Quality Assurance and Monitoring (QAM) reports prioritize putting into action the ameliorations of our inequity.
- Autistic professionals work as communication supports for each other under our Peer Mentorship model. This is in line with the peer support model that we originally discussed in our 2014 proposal.
- Peer support is an evidence-based method. This innovation has changed the course of each individual’s career and economic self-sufficiency outcomes.
- Innovate by liberating the inequity of traditions of dissemination of scientific research
- Our professional collaborations have launched a revolutionary genre of legislation through 2030; proposed by autistic professionals who bring scientific research to policy discussions and analyses.

Our evidence-based programs are innovative and practical, such that they provide job opportunities for autistic researchers, and have been designed to:

- Self-generate data on efficacy
- Provides a 5-year projection
- Focus on establishing state and federal standards for frontline workers (Police Departments, First Responders, state employees, etc.)
- Maintain a legally-binding, evidence-based process that is informed by the sum total of autistic culture and lived experience.

WHO ARE WE? Our research agenda is to generate a database of medical autism research for comparison of new research on neurodiversity culture. Our demographics are autistic adults who experienced marginalization and oppression because they are disadvantaged by the nature of their communication style. Please allow us to help you care about and understand us.

¹³ Kupferstein, H. (2020) Able Grounded Phenomenology (AGP): Toward an Ethical and Humane Model for Non-Autistic Researchers Conducting Autism Research. (Doctoral Dissertation, Saybrook University: [ProQuest](#)).