

From: Henny Kupferstein and Rebecca Botta-Zalucki

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

CC: Brian Coffin, Legislative Director
Nicole V. Parisi, Director of Operations

February 8, 2016

Dear Assemblyman Santabarbara,

We are submitting this proposal to summarize our requests for language and draft revisions to the legislation encompassing Autism Action NY, expected to be introduced this year. Your dedication to A.5141, and your devotion to helping change the ways in which ACCES-VR understands and serves autistic consumers, are held in very high esteem. Forming linkages between each piece of legislation in the package adds significant value to the legislative intent of Autism Action NY.

Powerful initiatives are most effective when organized and created by those who can base their input on direct, lived experience and appropriate credentials. Initiatives that disregard the intended beneficiaries are counter-productive, because they are self-contradictory. Employing the experience and credentials of those who are most directly affected by autism will make New York once again the model state for crafting autism legislation to best serve a broad range of need.

The following statewide advocacy and professional organizations support this proposal:

- (1) Autism Society of the Greater Capital Region
Janine Kruiswijk, Executive Director
101 State Street, Schenectady, New York 12305
(518) 355-2191
www.albanyautism.org

- (2) Finger Lakes Independence Center, Ithaca, NY
Jan Lynch, Executive Director
(607) 272-2433
jan@fliconline.org

- (4) Asperger Syndrome & High Functioning Autism Association
Pat Schissel, LMSW, Executive Director, AHA
office: 888.918.9198 direct: 516.662.3121
pats@ahany.org

- (5) David H. Minot, BA
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- (6) The Global and Regional Asperger Syndrome Partnership, Inc.
Kate Palmer, MA, CCP, CAS, GRASP President/CEO
419 Lafayette Street, New York, New York 10003
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kpalmer@grasp.org

- (7) Autistic Self-Advocacy Network of New York City
Elizabeth Rosenzweig, Chapter Leader
asan.nyc@gmail.com
(347) 915-3529

- (8) Long Island Center for Independent Living, Inc.
Joan Lynch, Executive Director
JLynch208@aol.com

- (9) Habitat for Humanity Capital District
Christine Schudde, Executive Director
325 Washington Ave. Ext., Albany, NY 12205
(518) 462-2993 x104
Christine@HabitatCD.org
- (10) NYSACRA - New York State Association of Community and Residential Agencies
240 Washington Avenue Ext., Ste. 504, Albany, NY 12203
(518) 449-7551
www.nysacra.org
- (11) NYSRA - New York State Rehabilitation Association, Inc.
155 Washington Ave., Ste 410, Albany, NY 12210
(518) 449-2976
www.nyrehab.org
- (12) WIB, Inc./Chautauqua Works
Carol A. Smith, Disability Resource Coordinator
23 East Third Street, Jamestown, NY 14701
407 Central Avenue, Dunkirk, NY 14048
716-487-5127, TDD/TTY – 716-487-5117
csmith@chautauquaworks.com
- (13) Families Together in New York State
Paige Pierce, CEO
737 Madison Avenue, Albany, NY 12208
518.432.0333 x12
ppierce@ftnys.org

(14) CUSP Educational Services LLC.
Stephen T. Motto, Owner/CEO
PO Box 66367, Albany NY 12206
(518) 203-3913
Steve@cuspservices.com

(15) NYSARC, Inc.
29 British American Blvd.. Latham, NY, 12110
(518) 439-8311
<http://nysarc.org/>

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

Sincerely,

Henny Kupferstein and Rebecca Botta-Zalucki

Two handwritten signatures in black ink. The signature on the left is more fluid and cursive, while the one on the right is more structured and blocky.

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Autism Action NY 2016

Advisory Board, ID Card, Housing, Technology, and Communication

Prepared by: Kupferstein, Henny, & Botta-Zalucki, Rebecca, February 2016

Autism Action NY 2016 is an example of diligence and compassion by policymakers and is destined to be a legacy for Assemblyman Angelo Santabarbara of the 111th New York State Assembly District. We are recommending changes to the proposed legislation and predict that the successful launch of this five-pronged legislative approach will serve all appropriate supports and reduce the state expenditures for adults dependant on SSI/Medicaid from \$12 trillion¹ annually to \$6 trillion (50% decrease) in the next five years.

We are proposing that the four new Autism Action bills that are packaged with A.5141, be revised to represent the broadest range of autistic people in the state.

- 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.
- The Autism ID Card (A.8389) shall have pre-formatted text built into the bill, in order to standardize the language as preferred by autistic people, or have three cards in-line with each DSM level for autism.
- 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 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.
- Communication Support (A.5141) shall be implemented by ACCES-VR in order to support people who are in the loan program to achieve financial independence through career training.

Autism Action NY plan for 2016 needs to include autistic individuals. This will ensure that autistic individuals with appropriate credentials will have a voice when serving the needs of people by borrowing from the peer-support model, a highly effective service delivery model. In addition, we identify the funding streams already in place which can be applied to the proposed services and systems of reform.

¹ Medicaid Expenditures for Selected Categories of Service by Category of Eligibility - January 2014 - March 2014, Retrieved from https://www.health.ny.gov/statistics/health_care/medicaid/quarterly/aid/2014/q1/expenditures.htm

Objective

Revising the language of Autism Action NY legislation to include the engagement of autistic individuals in the dissemination of autism-related information and implementation of the proposed support-delivery models (*Click designated bill numbers as hyperlinks for complete bill text*).

1. **Autism Spectrum Disorder Advisory Board** ([A.8635](#)) to consist of autistic members who are also professionals or parents, and hired by leading state agencies in administrative roles.
2. **Autism I.D. Card** ([A.8389](#)) to contain standardized terms that accurately represent autism with language established by autistic people.
3. **Autism Home Loan Program** ([A.8696](#)) to expand the opportunities for state loans to individuals who will otherwise not qualify for a bank loan due to chronic unemployment and poverty. The contingency for repayment is to sustain an active case with ACCES-VR for training towards employment and financial independence. The HOFA grant would allow for a steep cut on the school and property taxes in order to bring the monthly costs into the range of a fixed income.
4. **Technology Bill of Rights** ([A.8708](#)) to eliminate loan hurdles and make information accessible. Technology to be approved by autistics and the Advisory Board.
5. **ACCES-VR Communication Support** ([A.5141](#)) to be implemented by ACCES-VR to help the influx of home-owning applicants prepare for gainful and meaningful employment, redeeming themselves from the cycle of poverty.

New York State evidence identifies: The majority of autistics (80%) have average or above-average IQ; 77% are Caucasian, 44% are collecting SSI, and the majority of autistics (SSI Blind & Disabled²) on Medicaid statewide are in Suffolk County. NYSILC offices, specifically Albany County, provides services to the highest number of people with disabilities. The Joint Budget Hearing - New York State Department of Health/Medicaid (2016) reported that, throughout the past few years, the highest growth in the number of Medicaid recipients has been in upstate New York.

A. NY State Autism Spectrum Disorder Advisory Board (A.8635)

The Autism Spectrum Disorder Advisory Board (ASDAB) shall be charged to submit an annual Autism Action Plan governed by best practices. This plan shall summarize the research collected in the duration of the year in service. The members will need to travel to hearings across the state in order to gather data on best practices in each region. The board shall be comprised of 19 appointees who are representatives of leading state agencies.

² Retrieved from https://www.health.ny.gov/statistics/health_care/medicaid/eligible_expenditures/el2013/2013-cy_enrollees.htm

Recommendations for Language/Concept Change

Ideally, the ASDAB shall consist of 100% autistic members or similar to governing rules of Independent Living Centers, there should be at least 51%. There is a need to reframe the cultural landscape such that complete societal inclusiveness for autistic people can be achieved. This can only be accomplished if organizations and systems which are not-autistic, or people who have no lived experience, are willing to step aside and let individuals who hold the autism diagnosis have a say in the services that are being designed specifically for them. It is common for non-autistic individuals to fall prey to the false assumption that autistic people are not capable of making their own decisions, or offering suggestions and recommendations on the most effective services and supports to meet their needs.

Analysis of Current Board / Representation Proposed

Currently, the bill is drafted to require the ASDAB to consist of 19 members:

- 10 appointed
 - 2 appointed by the Governor
 - 2 appointed by the President of the Senate
 - 2 by the Speaker of the Assembly
 - 2 by the Minority Leader of the Senate
 - 2 by the Minority Leader of the Assembly
- 9 serve *ex officio*

New York has a history of state advisory boards supporting people with disabilities, failing to provide the necessary research that is needed for critical change in services. The basis of these failures is the fraternizing and recycling of representatives from state agencies who lack the lived experience to inform their work.

Cited examples:

1. In our April 25, 2014 proposal regarding Communication Support, the State Rehabilitation Council (SRC) where they struggled to find the means to publish a report on how to change employment outcomes for autistic consumers. For more than ten years, every report said “more information is needed.” When we submitted our proposal to the Deputy Commissioner of State Ed, our “information” was disregarded because it was written “outside the organization.”
2. The reports made by the New York State’s Interagency Task Force (Bill S02527A) on Autism to the Governor and Legislature and Board of Regents never mentioned adults except once and in the context of the Wildwood School Transition Program. The council is comprised of twenty-eight members, none of which include an expert with lived experience.

3. The more recent Senate Coordinated Children's' Services Initiative (Bill S3873) provides for coordinated children's services for children and youth with cross-system needs. The CCSI board *does not require* a single disabled member to be included on the board.

We strongly recommend leading state agencies consider hiring a credentialed autistic professional, with lived experience, to serve in an administrative role, in order for the agency to earn and sustain representation on the ASDAB. This allows the agency to hear from the voice of the people who they aim to support and enhance the service models they implement. In addition, this opens the doors for employment and leadership based on the peer-support model proven to be effective in many populations.

Peer Support

Peer support is an evidence-based system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful (Mead, Hilton & Curtis, 2001). The role of peer support in mental health services and person-centered recovery has been actively developing and evolving for more than two decades (Davidson, Chinman, Kloos, Weingarten, Stayner & Tebes, 1999). According to the Commonwealth of Massachusetts, Department of Public Health, "Peers, people who have experience in coping with and recovering from mental illnesses and substance abuse, are in unique positions because of their personal experience to provide health literacy and help others manage their symptoms, and develop hope for the future" (as cited in Solomon, 2004).

Peer support has proven efficacy, notably through demonstration projects, such as the creation of a Peer Bridger Project of peer support, developed through NYAPRS in 1994. The Peer Bridger Project trained and supported individuals with successful management of their mental health recovery through the engagement of positive, supportive relationships with peers, involvement in peer support meetings, follow-up with peers after discharge from hospitals, linking broad range community-based services and natural supports, and teaching peers community adjustment and wellness of self-management skills.

Other NY organization such as the Independent Living Centers, Youth Power! and the Autistic Self-Advocacy Network (ASAN) have embraced the peer support model. To highlight the importance of peer support, ASAN's co-founder Ari Ne'eman was appointed by President Barack Obama to the National Council on Disability to serve on the Council in 2010. He currently chairs the Council's Policy & Program Evaluation Committee. Ne'eman is the first autistic person to serve on the council.

Value of Lived Experiences

Autism should not be mistaken for an intellectual disability. In 2014, a U.S. study found that almost half of children with ASD had average or above-average intelligence, that is, an IQ score above 85. Less than a third of the children with autism had intellectual disability, and 23% had

IQ scores in the “borderline range” from 71 to 85³. We must also take into account those autistic people who test poorly on standardized measures designed to exploit language differences. In other words, at least 80% of autistic people have the ability to make sound, rational decisions and contribute to their own treatment.

In line with the peer support model, there is a growing list of educated and credentialed persons with autism comprised of both parents and professionals who are eager to be appointed to serve on the ASDAB. These individuals are willing to lend their expertise and support through lived experience and professional training. We are proposing that the ASDAB be comprised of at least 50% autistics, which will ensure a revolutionary level of attention to the needs and concerns of autistic people.

Hiring and/or engaging volunteer advisors who are qualified autistic professionals in varying administrative roles sets the stage for change. This will allow meaningful autistic representation for the agencies in the advisory board and will also set an example for lesser-funded agencies to follow suit and take the path to empowering the people.

Eligible Candidates for Consideration

As is true for autistic adults (and the writers of this report), dozens are qualified and eager for the opportunity to serve. This list represents a summary of residents of NY with college degrees and often a professional license. In some cases, they are also parents, spouses, and/or caregivers. All are interested in being considered as candidates.

1. James G. Burke, jgburke@syr.edu BA in Religion and Society, Syracuse University, May, 2013. Types independently to communicate. TASH board member
2. Jennifer Cole, DSW
Social Worker, Parent, Adjunct Professor, University at Albany, Prevention Clinician at Trinity Alliance of the Capital Region, Inc.
3. Rebecca Botta-Zalucki, MSW (2016) botta.rebecca@gmail.com
Graduate student, Master of Social Work candidate, May 2016, Albany
4. Melanie Hecker melanietheproud@yahoo.com / melaniemotivates.com
Undergraduate student, Serves on Youth Power Board, Colonie
5. Andrew Haber, JD ashelred@gmail.com
Retired attorney with the New York State Department of Taxation and Finance.
Brooklyn Law School, 1976, JD Law, University at Albany, SUNY, 1973, Economics, minor math. Lives in Albany with wife Kate Gladstone
6. Kate Gladstone, Master’s in Library Science (Long Island University, 1989), Honors BA in Linguistics (University of Pennsylvania, 1987), handwritingrepair@gmail.com

³ Autism and Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators. (2010). Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years – Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010. Retrieved from http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm?s_cid=ss6302a1_w

Member of the Autism Society of America's national-level Program Committee and its national-level Committee of Spectrum Advisors, CEO of HandwritingThatWorks.com, Albany. Married to Andrew Haber.

7. Michele Vics catwoman3181@gmail.com
Medical biller, Schenectady
8. David Griffin, BA, Earth Science dgriffi2@nycap.rr.com
Environmental Engineering Technician, NY State Department of Environmental Conservation. Homeowner in Colonie
9. Amy Gravino, amy@amygravino.com Port Jefferson, NY
MA, CAS, autism consulting and college coaching for autistic students
10. David Dwyer beeze26@hotmail.com
Senior car mechanic, resides in Albany
11. Andrew Crippen, sacrip@yahoo.com
Army veteran, Employee of Department of Corrections and Community Services.
Resides in Hudson.
12. Jocelyn Therese Eastman shazaamoon@aol.com, BS in Mathematics, MA in Education,
Resides in Oneida
13. Jessica Davis, (Jocelyn's twin), BA History from SUNY Albany,
vadsha@aol.com and papirini@gmail.com. artist and bill drafter, Albany
14. Elizabeth Rosenzweig, rosenzweig.ea@gmail.com, asan.nyc@gmail.com
Emerging Scholar in biomedical informatics at CUNY, student researcher at the Center
for Molecular Biophysics at USDOE Oak Ridge National Laboratory
15. Michael Gilberg, JD, michaelgilbergesq@gmail.com
JD, Pace University. Attorney specializing in special education law.
16. Imeh Smith, BA from Howard University sogwa@circlesedgeinc.com
Writer, artist, and founder of The Circle's Edge, Inc.
17. Dylan Emmons, MFA in Writing, Sarah Lawrence College dylan.emmons@sunywcc.edu
Adjunct Professor of English at Westchester Community College, Mount Vernon
18. Molly Kampfsdottir, loki.laufeydottir@gmail.com
Game Designer, Transgender activist, Clifton Park
19. Marc Rosen, marc.rosen88@gmail.com
Author and Editor, disability and accessibility consultant, Treasurer, Board of Directors:
Youth Power, Inc., Former Disability Integration Adviser Reservist for FEMA

B. Autism ID Card (A.8389)

The legislation would provide New Yorkers diagnosed with an Autism Spectrum Disorder the option of obtaining an identification card that would assist in their interactions with law enforcement and in emergency situations. The card is designed to serve as a uniformed

mechanism that will convey information about a person's diagnosis, such as trouble following directions and an aversion to physical contact or shared space.

Recommended Language / Content Change

As important as it is for the card to be standardized for ease of use and rapid recognition among first responders and other individuals, autism is a spectrum disorder; it manifests differently in each person who has the diagnosis. Therefore, we propose that autistic people design the cards' standardized language, each matching the three DSM levels for autism, and allow for cardholder personalization on a space on the card, below the standardized section, to be designated for handwritten statements conveying limitations specific to the cardholder.

The language of these recommendations must be explicitly written into the bill in order to eliminate the patchwork of local agencies and officials who have fragmented knowledge of the lived experience of autistic people themselves.

QR Codes

A QR code is a free technology that maximizes independence and privacy for cardholders via a scannable image that can be printed onto a sticker and replaced as needed. For example, the webpage <http://goqr.me/> allows anyone to enter a complete body of text free of charge, and generate a large QR code image (pictured at right). If you have a scanner or QR app (free), you can see a sample of personal information from this QR code pictured here (fictitious person). *Please scan the barcode with your phone to access the information.* QR codes can be rendered in tiny sizes too. Scannable codes also protect the cardholder from being mandated to keep their information up-to-date in an online database. Codes can be modified as often as needed, reprinted, and reapplied to the card whenever there are personal updates such as medication, doctors, and accommodation needs.



Version I - Identity First Language, Level I Diagnosis

Front	Back
<p>I Am Autistic</p> <p><i>I am giving you this card because:</i></p> <ul style="list-style-type: none"> ➤ I may be experiencing difficulty with communication. ➤ I am likely to appear anxious ➤ I may behave defensively or threatening ➤ I am averse to physical contact. <p style="text-align: center;">Autism is not an excuse for illegal behavior.</p> <p style="text-align: center;">I am not intentionally refusing to cooperate.</p> <p><i>I may need your assistance...(over please) ↪</i></p>	<p>Scan this QR code for emergency information about me.</p>  <p style="text-align: center;">Additional Info:</p> <div style="border: 1px solid black; border-radius: 15px; height: 80px; width: 100%; background-color: #e0f0ff;"></div> <p>If this is a legal matter, I will need communication support. Visit the autism-society.org website and connect with a local affiliate.</p>

Version II - Person's First Language, Level II Diagnosis

Front	Back
<p>I Have Autism</p> <ul style="list-style-type: none"> ➤ I have communication difficulties ➤ I am likely to appear anxious ➤ I may behave defensively or threatening ➤ I do not like to be touched <p style="text-align: center;">Autism is not an excuse for illegal behavior.</p> <p style="text-align: center;">I am not intentionally refusing to cooperate.</p> <p><i>I may need your assistance...(over please) ↪</i></p>	<p>Scan this QR code for emergency information about me.</p>  <p style="text-align: center;">Additional Info:</p> <div style="border: 1px solid black; border-radius: 15px; height: 80px; width: 100%; background-color: #e0f0ff;"></div> <p>Emergency Contact:</p> <hr style="border: 0.5px solid black;"/>

Version III - Person's First Language, Level III Diagnosis

Front	Back
<p>I Have an Autism Spectrum Disorder</p> <p>➤ I may have difficulty understanding and following your directions or may become unable to respond.</p> <p>➤ I may become physically agitated if you prompt me verbally or touch me or move too close to me.</p> <p>Autism is not an excuse for illegal behavior.</p> <p>I am not intentionally refusing to cooperate.</p> <p><i>I may need your assistance...(over please) ↪</i></p>	<p>Scan this QR code for emergency information about me.</p>  <p>Additional Info:</p> <div style="border: 1px solid black; border-radius: 15px; height: 80px; width: 100%; background-color: #e0f0ff;"></div> <p>Please call my emergency contact immediately:</p> <hr/> <hr/>

C. Home Loan Program (A. 8696)

This bill is modeled after successful legislation in the states of Massachusetts and Pennsylvania. The bill sets up funding in the budget for a loan program. With this bill, families can leverage their own money to add an accessory unit to the home they own and live in, to house their adult child. Families can get an interest free, potentially deferred payment loan for up to \$50K or 50% of construction costs.

This proposal would add a new paragraph (i) to subdivision 7 of section 45-b of the private housing finance law to establish this accessory apartment loan program. This unit will be financed by a loan from the state budget, and repaid to the state in standard loan terms. While this is only revenue-neutral for the state, it helps families establish independent housing situations for their offspring without being burdened by loans from private banks, which often have exorbitant interest rates.

Recommendations for Language Change / Content Change

Three amendments are recommended to this bill:

1. Establish a HOFA (Homeownership Opportunity For Autistics) grant for exemptions on state and property taxes.
2. Expand the state loan criteria to include autistic adults interested in purchasing a home while on a fixed income.

3. Designate Independent Living Centers as the administrators of the loans.

HOFA Grant Description

The proposed Homeownership Opportunity For Autistics (HOFA) grant program is modeled after the STAR grant⁴ in New York and Maryland's (HIDP) Homeownership for Individuals With Disabilities Program⁵.

- Term: 30 years
- Minimum Cash Contribution: \$500.00 (entire amount can be gifted).
- Mortgage Insurance/Guarantee: Not required
- Co-signers: Permitted
- Eligible Jurisdictions: Available statewide where median home price does not exceed 10% of Social Security benefit per year.
- Eligible Properties: Existing or newly constructed homes. Newly constructed homes must be in Priority Funding Areas only
- Minimum Credit Score: >600 , one year of satisfactory credit history required. An exception to this policy will be considered if the paid collection account or judgment was a medical account with a nominal balance and applicant has a reasonable explanation why the account was delinquent.

An applicant shall have an autism diagnosis from a credentialed professional. Exemption requirements:

- the individual's disability of autism
- income
- residency
- ownership

Residency requirements - The property shall be the "legal residence" of the autistic person and must be occupied by that person unless he or she is absent from the property while receiving health-related services as an inpatient of a residential health care facility (a residential health care facility is a nursing home or other facility that provides lodging, board, and physical care including, but not limited to, the recording of health information, dietary supervision, and supervised hygienic services)

The property shall be used exclusively for residential purposes. If a portion of the property is used for other than residential purposes, the exemption will apply only to the portion that is used exclusively for residential purposes.

A "Certificate of Disability" completed by a health, mental health, or disability professional is required. The applicant shall submit one of the following:

⁴ Exemption for a household combined income below \$500k, <https://www.tax.ny.gov/pit/property/star/index.htm>

⁵ http://www.dhmf.maryland.gov/mha/Documents/Resource%20Guide%20Update%202011%20final_online.pdf

- Diagnostic report or diagnosis verification letter from a licensed psychologist.
- Award letter from the Social Security Administration certifying the applicant's eligibility to receive Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI)
- Certificate from the State Commission for the Blind and Visually Handicapped stating that the applicant is legally blind
- Award letter from the United States Department of Veterans Affairs stating that the applicant is entitled to a veterans disability pension

If the award letter or certificate states that the applicant's disability is autism (which is permanent), there will be no need to re-file evidence of disability in future years if renewal of the exemption is sought.

Income requirements:

If a Federal or New York State income tax return was filed for any of the owners of the property or their spouses for the preceding year, copies of such return should be submitted with their application. Income is to be reported on the basis of the latest preceding "income tax year" prior to the date of application. This usually is the preceding calendar year.

Non-Taxable Income: If a particular source of regular income is not subject to federal income taxes (for example, certain types of disability and public assistance payments, military allowances), the amount of continuing tax savings attributable to the non-taxable income will be added to the borrower's gross income when calculating the borrower's underwriting ratios. The percentage of income that is added is the appropriate tax rate for that income amount. If the borrower is not required to file a federal income tax return, the tax rate that will be used is 25 percent.

If the person is married, the income of his/her spouse shall be included in the total unless his/her spouse is absent from the residence due to a legal separation or abandonment. The income of a non-resident former spouse who retains an ownership interest after the divorce, is not included.

Income includes:

- disability payments
- all Social Security payments
- salary and wages (including bonuses)
- interest (including non-taxable interest on state and local bonds)
- total dividends
- net earnings from farming, rentals, business or profession (including amounts claimed as depreciation for income tax purposes)
- income from estates or trusts
- gains from sales and exchanges
- the total amount received from governmental or private retirement or pension plans
- annuity payments (excluding amounts representing a return of capital)

- alimony
- unemployment insurance payments
- workers'€™ compensation
- etc.

Municipalities have the option to permit applicants to subtract from their incomes all medical and prescription drug expenses that are not reimbursed or paid by insurance.

If the owner is an inpatient in a residential health care facility, the owner's€™ other income is not considered income in determining exemption eligibility if it does not exceed the amount paid by such owner, spouse, or co-owner for care at the facility. Proof from the facility of the amount paid for an owner's€™ care must be submitted with the exemption application.

Social Security payments received by an owner as representative payee of another is not considered income. If the recipient can prove that the monies he or she receives are paid on behalf of another, such as the recipient's disabled adult child, those monies received in a fiduciary capacity are not considered income to the recipient.

Ownership requirements - All of the owners shall have a verified diagnosis of autism. Exceptions are not made in cases where the property is owned by parent, partner, or by siblings.

- **Life estates and trusts** - The life tenant is entitled to possession and use of the property for the duration of his or her life and is deemed the owner for all purposes, including taxation. The exemption also may be allowed if the property is in trust and all the trustees or all the beneficiaries qualify.
- **Cooperative apartments** - Municipalities are authorized to grant the exemption to seniors who own shares in residential cooperatives. If granted, you would receive adjustments to your monthly maintenance fees to reflect the benefit of that exemption.
- **School-age children** - If you have children living in your home and attending public school, you generally are not eligible for the Exemption for Autistic Adults. If the child attends a private or parochial school, you can still receive the exemption.
- **School districts** can opt to offer the exemption even if the children in the home are attending public school. However, the school district must require satisfactory proof that the child was not brought into the residence primarily for the purpose of attending a particular school within the district.

Recommendations, Analysis, and Justifications

Currently, the bill asks that a new provision be added to the existing private housing finance law, specifically assigning the administrative duties of this loan to a public benefit corporation known as the "Affordable Housing Corporation". Under 6(f) this corporation may "Engage the services of private consultants on a contract basis for rendering professional and technical assistance advice".

Recommendations 1

The Independent Living Centers be designated as the agency to facilitate, monitor, and distribute these grants, given that they service the roughly 80% of autistics who are not eligible for OPWDD grants and services.

Recommendation 2

We propose a HOFA grant for eligible autistics, details below (See Addendum 1).

Forming linkages between A.8696 (Home Loan) and A.5141 (Communication Support) adds significant value to the legislative intent of Autism Action NY. We strongly recommend that the bill allow for disabled individuals who may be on fixed incomes to receive a tax-free home loan from the state. The HOFA grant would allow for a steep cut on the school and property taxes in order to bring the monthly costs into the range of a fixed income.

A revitalization of depressed areas around the Capital Region — a secondary benefit of our recommendation—will link new homeowners to job opportunities (i.e. with leading state agencies in close vicinity), foster investment in upstate communities, and generate economic growth (A. 8004).

The loans shall be deferred for five years or until the ACCES-VR case is closed after a successful employment outcome. Otherwise, the loan total costs must be within the monthly benefits (less than \$800/month for SSI) to be repaid from Social Security income. This provision will eliminate discrimination in the housing market for people on fixed incomes who cannot secure a bank loan due to chronic unemployment.

The recommendation has the potential to generate buy-in from key stakeholders. One way to accomplish this is to show stakeholders how the success of our proposed initiative can be measured. On researching long-term efficacy, new homeowners' quality of life outcomes may be measured using pre-post instruments such as questionnaires, interviews, and surveys.

D. Communication & Technology Bill of Rights (A.8708)

Technology and information access by people with developmental disabilities must be guided by standards and best practices, such as personalization and compatibility across devices and platforms. This bill would require all state agencies and authorities to implement best practices and standards in the dissemination of information from their official websites, ultimately create new markets and employment opportunities; decrease dependency on public services; reduce healthcare costs; and improve the independence, productivity and quality of life of people with developmental disabilities.

Recommendations for Language / Content Change

State and local agencies that work directly with consumers one-on-one such as ACCES-VR or DSS, often do not share a complete list of services available to consumers. A full menu of services should be explicitly posted on webpages in several formats for accessibility — to make known the options available to people who might be eligible. Formats should include:

1. Charts and graphs for visual learners
 - a. People who have dysgraphia, dyslexia, ADHD, and/or visual disturbances may struggle to sustain eye tracking necessary for reading charts. Bus schedules, office hours, and text on multiple columns can be difficult to process.
2. Dynamic flowcharts for visual thinkers
 - a. Visual thinkers will struggle to put into words what they are looking for and this method reigns in the overwhelming need to search for the right link to click on. A flowchart will ask a single question and then produce a response in logical sequence based on the first question. The website visitor must have the option to revise his or her answers at any point in order to be prompted to the next menu. The flowchart will walk each visitor through the system, in order to match individuals to the areas most closely related to their inquiries.
3. Videos for auditory learners
 - a. All videos must have closed captions for users who are deaf or have auditory processing difficulties. As many as 53% of the population at large will require audio instructions in order to learn about services available to them.⁶ All videos must contain a full transcript on the page below for review of references or information mentioned in the video.

State and local agencies must be required to consult with the **State Autism Spectrum Disorder Advisory Board (A.8635)** in order to hear from people with learning disabilities and to seek their input on planning, design, and implementation before launching multi-formatted service menus and systems.

⁶ Kupferstein, H., & Walsh, B. J. (2015). Non-Verbal Paradigm for Assessing Individuals for Absolute Pitch. *World Futures*, 1-16.

Addendum 1

To Section C. Home Loan Program (A. 8696)

Recommendations for Language Change / Content Change

HOFA Grant Description

Recommendations, Analysis, and Justifications

C-I. Housing Grants Compared to Dependency Benefits

Here we compare the cost of the state's expenditures for dependent adults, alongside the potential costs to the state budget for a grant towards tax exemptions. The premise of the comparison is to be conscientious of the state investment in loans that will be repaid, versus benefits that will never be repaid, making this grant a budget-neutral solution for trillions of dollars in expenditures for dependent adults.

C-II. Costs by Highest Dependency County

A zillow.com home prices in Suffolk County (where there are the highest number of disabled Medicaid recipients in the state) shows an example of a listing under \$200,000:

- 2 bedroom / 2 bathroom foreclosure asking \$199, 0000 in Central Islip
- Purchase price \$199k, property taxes for 2014 \$6000/year (\$508/month).
- Homeowner's insurance, at least \$800-\$1500/year (\$100/month minimum)

Among all types of jurisdictions, the highest property tax was found in Binghamton, at \$58.28 per \$1,000, or \$4,959 a year (\$413/month) for a home at Binghamton's local median value of \$85,100. The lowest rate in the state is \$4.57 in the Suffolk County village of Southampton.

Reasonable & Affordable: A zillow.com home in Calverton, (Suffolk County):

- 2 bedroom / 2 bathroom foreclosure asking \$69,000 zip code 11933
- Property taxes \$69/month
- Homeowner's insurance, \$67/month

C-III. State Expenditures on Benefits in Suffolk County

Costs of benefit payouts for Medicaid in Suffolk County in Calendar Year 2013⁷:

- Total 34,790 enrollees (average \$790/month = \$27,484,100)
- 21,262 SSI enrollees for "SSI & Medicaid Subsistence Blind & Disabled"
- 13,528 enrollees for "Medicaid Blind & Disabled"
- 224,294 total Medicaid enrollees in Suffolk county, the highest in the state.

⁷ https://www.health.ny.gov/statistics/health_care/medicaid/eligible_expenditures/el2013/2013-cy_enrollees.htm

C-IV. Comparison with Exemptions

Cost to the state for the 5-year deferred tax-free loan:

- Number of people eligible by virtue of autism diagnosis: 200k+ in New York, 2016
- Average \$100,000 per loan, to be repaid in full starting in five years. If 25,000 people apply, the loan amounts total to \$2,500,000,000
- STAR Program grant in Suffolk County Town of Southampton⁸:
 - School District's Maximum 2015-2016 STAR Saving by School Districts - Basic \$91 or Enhanced \$192 savings
 - School District's Maximum 2015-2016 STAR Savings by Municipality - Basic \$135 or Enhanced \$288 savings
- Cost of STAR grant (\$288 for 25,000 applicants)
 - \$86,400,000 / year for 25,000 applicants
 - or \$2,592,000,000 for 25,000 applicants with a 30-year loan
- Proposed HOFA Grant cost of to slash property taxes

C-V. ACCES-VR Linkage Explanation

As stated previously, forming linkages between A.8696 (Home Loan) and A.5141 (Communication Support) adds significant value to the legislative intent of Autism Action NY. Linking homeownership (A.8696) to ACCES-VR and Communication Support (A.5141) will enhance the comprehensive nature of this package of legislation. These legislative tools will help catapult a paradigm shift for an underrepresented sector that yearns for leadership and research opportunities.

According to Barbara Arisohn, District Office Manager of the Albany District Office for ACCES-VR, “It is ACCES-VR’s customary practice to identify a broad employment goal when a consumer expresses interest in obtaining an advanced professional degree”⁹. Vocational Rehabilitation Policies and Procedures omits information in the mission and state policy documents specifying that VR reserves the right to “identify a broad employment goal”. Rather, in “A Guide for Developing Your Individualized Plan for Employment (IPE)”, some of the things an ACCES-VR Counselor must consider include: (1) Is the goal consistent with your abilities, capabilities, and interests? (2) Will the services result in employment?

When the writers of this proposal met with the Assistant Commissioner of ACCES-VR and the Director of Quality Assurance in the spring of 2014, both the Assistant Commissioner and Director of Quality Assurance informed us that we were correct when we stated ACCES-VR is not equipped to help people with autism. These two individuals informed us that they were aware of the problem and would actively seek out remedies to correct the issue.

⁸ <https://www.tax.ny.gov/pit/property/star/sd47.htm>

⁹ Email correspondence, Jan 28, 2016

The State requires ACCES-VR to monitor “participation and outcome measures for those individuals...who are considered at risk for being underserved by the VR Program in context to the broader employment system”¹⁰. In regards to the statutory regulations on informed choice, “all activities are to be implemented consistent with the principles of respect for individual dignity, personal responsibility, self-determination, and pursuit of meaningful careers, based on informed choice, of individuals with disabilities.” (Id. § 701(c)(1)). It is imperative that Communication Support (A.5141) be implemented so that new autistic homeowners (A.8696) can sustain meaningful employment in-line with industry standards and in their areas of strength and interest.

C-VI. Projected Outcomes

A private home will significantly shift the numbers of autistic individuals’ achieving financial independence. The contingency to be approved for this program is to maintain an open case with ACCES-VR in order to assist in the achievement of meaningful employment. The passage of A.5141, Communication Support, will not only provide leverage for this program we are recommending, but will greatly improve the employment outcomes of individuals who apply for services with ACCES-VR.

The state can ultimately trade SSI expenditures for investments in new applicants’ loans. The loans will be returned, while SSI expenditures are never repaid. The trade-offs are instant the moment one home-owner has a successful outcome in achieving employment through ACCES-VR’s training and support and redeeming themselves from the cycle of poverty and dependence. ACCES-VR will have an incentive to assist its consumers pursue lasting employment in higher-paying fields consistent with their abilities, and gain financial independence since consumers participating in the loan program must pay expenses incurred from owning a home. We aim to create a new generation of homeowners who will not burden their county for benefits after the financial independence is achieved through Autism Action NY.

C-VII. Caught in the Web of Poverty

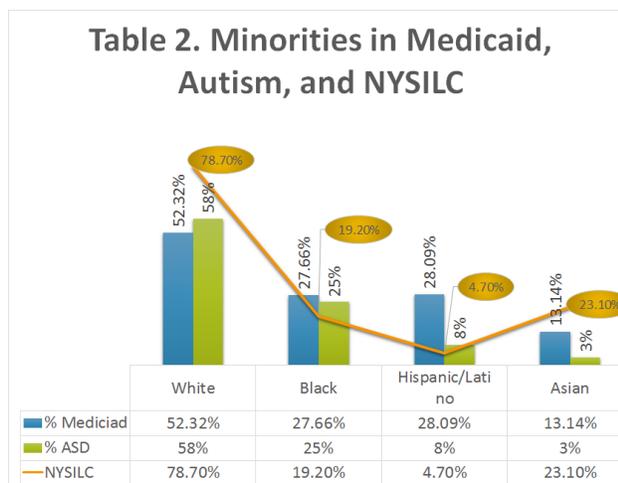
- Only **31%** of all autistics are diagnosed with a level-3 DSM diagnosis and an IQ at or below 70, requiring support for life.¹¹
- Only **17%** of OPWDD consumers are autistic.¹²

¹⁰ Federal Fiscal Year 2014, Strategies on Page 8, State’s Strategies and Use of Title I Funding for Innovation and Expansion Activities: Attachment 4.11, d

¹¹ Developmental, D. M. N. S. Y., & 2010 Principal Investigators. (2014). Prevalence of autism spectrum disorder among children aged 8 years-autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *Morbidity and mortality weekly report. Surveillance summaries (Washington, DC: 2002)*, 63(2), 1.

¹² Retrieved from http://www.opwdd.ny.gov/opwdd_community_connections/autism_platform

- **77%** (level 2 and level 1 severities) of autistics have average or above average intelligence, and are not eligible for OPWDD because of their adaptive functioning domains test above the level-3 cutoff.¹³
- Privileged white suburban autistics have a **1.59%** greater chance at obtaining a diagnosis (see Table 2).¹⁴
- **80% of autistics are not eligible for OPWDD, get state benefits.**¹⁵



Currently, Bill No A. 8696 focuses on single-family homes, not multi-unit dwellings and rentals or people who cannot utilize family support for an accessory unit. This will offer the majority of autistics (80% with average or above-average IQ) a chance to live their adult lives with appropriate housing and to enhance their trajectory toward emotional well-being and financial independence.

C-VIII. Federal and State Programs

Closing the gap between higher and lower income autistic individuals can be achieved if autism supports are readily available to struggling lower-income autistics caught in the web of poverty. Increased rates of employment help propel autistic adults toward financial independence and the ability to buy and own homes.

What happens to the 80% of adults who do not qualify for OPWDD?

NYSILC services this population because they have nowhere else to go.

¹³ Our calculation of 77% with IQ at or above-average, plus 3% for underdiagnosis in underprivileged minority, and the 1.59% greater chance in accessing a diagnosis for non-minority groups. We also conjecture that adults with above-average IQ are at a disadvantage for being diagnosed in childhood.

¹⁴ Thomas, K., Ellis, A., & McLaurin, C. (2007). Access to care for autism-related services. *Journal of Autism and Developmental Disorder*, 37(10), 1902-1912. doi: 10.1007/s10803-006-0323-7

¹⁵ Medicaid Source: Medicaid Quarterly Reports of Beneficiaries, Expenditures, and Units of Service by Category of Service by Aid Category by Region, 2014 Calendar Year, Monthly Average Beneficiaries, Retrieved from https://www.health.ny.gov/statistics/health_care/medicaid/quarterly/aid/. Autism calculation of 1 in 68, CDC estimates.

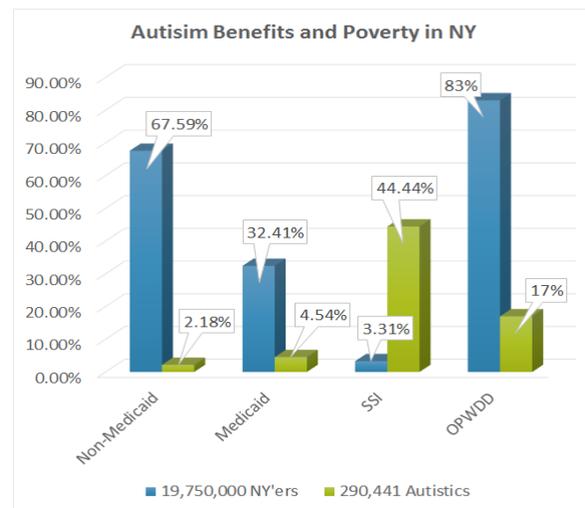
NYSILC 2015 Needs Assessment Report¹⁶
The New York State Independent Living Centers

Demographics of all disabilities in need of the most assistance from NYSILC	Needs of all disability groups by areas in dire need of assistance
42% Urban 78% White 54% 23-54 years old 46% Capital District 26% Developmental Disabilities 0% cognitive disabilities 45% LGBTQIA	43% most difficult: Finances (paying bills) Urban 46% most difficult: Finances (paying bills) Suburban 73% Housing and Shelter Services 69% Employment opportunities

C-IX. Financial Facts

- The annual benefits/poverty benefits rate for a New Yorker with a disability is \$12,568 (SSI/SNAP/HEAP)
- Over 15,000 renters are paying over 50% of their income on their housing expenses

Government statistics suggest that autism prevalence rates have **increased 17% annually** in the last few years¹⁷. This legislation seeks to allow a more flexible approach to housing at a time when hundreds of thousands of autistics are in need of immediate housing solutions.



[END OF PROPOSAL]

¹⁶ NYSILC 2015 Needs Assessment Report, Retrieved from <http://www.nysilc.org/images/NeedsAssesFinalRep.doc.pdf>

¹⁷ Jick, H., Beach, K. J., & Kaye, J. A. (2006). Incidence of autism over time. *Epidemiology*, 17(1), 120-121.