

Center for Autism and Related Disabilities (CARD)	1534 Western Avenue Albany, NY 12203	518-422-2574	https://www.albany.edu/autism
Autism Society of Western New York	19 Limestone Drive, Suite 1, Buffalo, New York 14221	716-633-2275	https://autismwny.org/
Autism Society of the Greater Capital Region	433 State Street 4 th Floor Schenectady, NY 12305	518-355-2191	https://www.asgcr.org/
AutismUp Headquarters	50 Science Parkway Rochester, NY 14620	585-248-9011	https://autismup.org/
Autism Council of Rochester	Check link various locations	(585) 413-1681	https://www.theautismcouncil.org/
St. Rose Friday Knights Program	432 Western Avenue, Albany NY 12203	800-637-8556	https://www.strose.edu/academics/schools/school-of-education/campus-based-professional-groups/friday-knights-program/
DDAWNY Family Committee		(716) 877-7007	http://www.ddawny.org/committees/family-committee/
Golisano Autism Center	Golisano Autism Center 50 Science Parkway Rochester, NY 14620	(585) 685-8300	https://www.golisanoautismcenter.org/

Appendix C

Self-Advocate Technology Recommendations

On November 13, 2019, the Autism Spectrum Disorders Advisory Board self-advocate workgroup convened to provide input on assistive technology, an issue which reflects one of the Board's recommendations to expand the use of technology in service delivery.

Below is a summary of their feedback.

When considering the types of technology used, and types of challenges assistive technology can help overcome, the most prominent sentiment was that this varies by individual. Autism is a spectrum, and a variety of technologies respond to a variety of needs. Technology should be personalized to each individual based on an assessment of skills, (personal and related to the community) as well as their needs and goals.

The technology used by people with autism is often the same as that used by people without disabilities. One example is the use of smart phones, and many standard features that may be of benefit to people on the spectrum (e.g. calendars and alarms for reminders).

Automated reminders may assist some people on the spectrum with memory and cues. Smart phones may also help provide a distraction for people when they may otherwise stim or exhibit (socially unacceptable) behavior that most people would not understand.

There are also technologies designed specifically for people with ASD. Many are designed for children (e.g. to assist with social skills). There is a hope that such technology could be adapted for use by adults as well, as such needs may continue through adulthood.

It appears there are more options specifically geared toward helping those with higher support needs (e.g. speech generation), while people with lower support needs typically adapt more generic technologies for their use.

It is important that information on technological service and support options be made available to those who create service plans including care managers, school districts/special education departments and staff members. This is complicated by the fact that technology is always changing. Parents will likely depend on staff and care managers to gain an understanding of the options available with smart phones.

In terms of newer technologies that self-advocates found promising, the *smart tower* was noted. This device uses sensors and reminders to provide prompts for the person using it and can also provide crucial information to the person's guardian (e.g. parent, support staff). For example, if a front door to the person's apartment opens at an unusual time (e.g. the middle of the night), a motion sensor will register the movement and send a text message to their parent or guardian. This allows greater personal independence for people

with support needs, as the smart tower helps maintain constant contact and provides for safety assurances to the parent and the person with the need.

Types of Technology Suggested/Commonly Used by Self-Advocates

- Apps
 - Calendar Alerts
 - Geo-tracking
 - Social Skills
- Disability robots
- Motion sensors
- Smart phones
- Smart tower
- Speech and communication augmentative technology
- Virtual assistants
- Voice to text on smartphone

Appendix D

Listing of Autism Research Resources

The New York State Autism Spectrum Disorders Board does not endorse any of the organizations' linked websites and does not endorse the views expressed or the products or services they offer. Additionally, the Board does not control or guarantee the accuracy, relevance, or completeness of information contained on a linked website.

Federal and State Government

Clinical Trials (search with keywords)	https://clinicaltrials.gov/
New Jersey Government Agencies	https://www.autismnj.org/information-services/government-agencies/
National Institute of Mental Health	https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index.shtml
Eunice Kennedy Shriver, NICHD	https://www.nichd.nih.gov/health/topics/autism
Interagency Autism Coordinating Committee	https://iacc.hhs.gov/
National Human Genome Research Institute	https://www.genome.gov/Genetic-Disorders/Autism
National Institute of Neurological Disorders and Stroke	http://www.ninds.nih.gov/disorders/autism/autism.htm
National Institute on Deafness and Other Communication Disorders	https://www.nidcd.nih.gov/health/autism-spectrum-disorder-communication-problems-children
U.S. National Library of Medicine Medline Plus	https://medlineplus.gov/autismspectrumdisorder.html
Centers for Autism and Developmental Disabilities Research and Epidemiology	https://www.cdc.gov/ncbddd/autism/caddre.html

University Center for Excellence in Developmental Disabilities

Rose F. Kennedy University Center for Excellence in Developmental Disabilities Education, Research and Service	http://www.einstein.yu.edu/cerc/
Westchester Institute for Human Development UCEDD in affiliation with New York Medical College	http://www.wihd.org
Strong Center for Developmental Disabilities, University of Rochester	http://www.urmc.rochester.edu

Research Database

PubMed (search with keywords)	https://www.ncbi.nlm.nih.gov/pubmed/
Clinical Trials (search with keywords)	https://clinicaltrials.gov/
Center Watch	https://www.centerwatch.com/clinical-trials/listings/condition/612/autism/
Interactive Autism Network	https://iancommunity.org/cs/research_studies/overview
National Institute of Child Health and Human Development Clinical Trials	https://www.nichd.nih.gov/health/topics/autism/clinicaltrials

University Centers

Association of University Centers on Disabilities	https://www.aucd.org/
Albany Center for Autism and Related Disabilities	https://www.albany.edu/autism/
Stony Brook	https://neuro.stonybrookmedicine.edu/centers/autism/team
SUNY Binghamton Institute for Child Development	https://icd.binghamton.edu/
University of Rochester Strong Center for Developmental Disabilities	https://www.urmc.rochester.edu/strong-center-developmental-disabilities/programs/rochester-regional-ctr-autism-spectrum-disorder.aspx
Golisano Autism Center	https://www.golisanoautismcenter.org/
Mount Sinai Seaver Autism Research Center	https://icahn.mssm.edu/research/seaver
Columbia University Center for Autism and Developing Brain	https://childadolescentpsych.cumc.columbia.edu/locations/center-autism-developing-brain-cadb
NYU Langone Child Study Center	https://nyulangone.org/locations/child-study-center/autism-spectrum-disorder-service
Weill Cornell Autism Research Program	https://pediatrics.weill.cornell.edu/research/weill-cornell-autism-research-program-wcarp
Hofstra University	https://www.hofstra.edu/community/slzctr/slzctr_institute_asd.html
Montefiore-Einstein Center for Autism	https://www.montefiore.org/cacd
Children's Hospital at Montefiore	https://www.cham.org/specialties-and-programs/neurology/conditions/autism-diagnosis-and-treatment
Maimonides Children's Hospital	https://www.maimonidesmed.org/maimonides-infants-and-childrens-hospital/pediatric-medical-services/development-and-behavioral-medicine
Rutgers Douglass Developmental Disabilities Center	https://gsapp.rutgers.edu/centers-clinical-services/douglass-developmental-disabilities-center
Children's Hospital of Philadelphia Center for Autism Research	https://www.centerforautismresearch.org/
Kennedy Krieger Institute, Johns Hopkins University	https://www.kennedykrieger.org/
Waisman Center, University of Wisconsin	https://www.waisman.wisc.edu/
Nisonger Center, Ohio State University	https://nisonger.osu.edu/
Marcus Center, Emory University	https://www.marcus.org/

Academic Associations

International Society for Autism Research	https://www.autism-insar.org/
Council for Exceptional Children	https://www.cec.sped.org/

Council for Exceptional Children Division of Autism	http://www.daddcec.com/
American Academy of Pediatrics Autism Initiatives	https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Pages/autism-initiatives.aspx
American Academy of Neurology Policy & Guidelines	https://www.aan.com/Guidelines/home/GuidelineDetail/33
American Academy of Child and Adolescent Psychiatry	https://www.aacap.org/aacap/families_and_youth/resource_centers/autism_resource_center/home.aspx
Association for Behavior Analysis, International	https://www.abainternational.org
Association of Professional Behavior Analysts	https://www.apbahome.net/
Cambridge Center for Behavioral Studies	https://behavior.org/help-centers/autism/

Autism Journals

List of Major Journals on Autism	https://www.omicsonline.org/autism-journals-conferences-list.php
<i>Journal of Autism and Developmental Disorders</i>	https://link.springer.com/journal/10803
Journal of Applied Behavior Analysis	https://onlinelibrary.wiley.com/journal/19383703
Behavior Analysis in Practice Autism	https://link.springer.com/journal/40617
Autism Research	https://journals.sagepub.com/home/aut
Autism Research and Treatment	http://onlinelibrary.wiley.com/journal
Autism Research and Treatment	https://www.hindawi.com/journals/aurt/contents/
Research in Autism Spectrum Disorders	https://www.journals.elsevier.com/research-in-autism-spectrum-disorders
Focus on Autism and Other Developmental Disabilities	https://journals.sagepub.com/home/foa
Education and Training in Autism and Developmental Disabilities Journal	http://daddcec.org/Publications/ETADDJournal.aspx
Behavioral Interventions	https://onlinelibrary.wiley.com/journal/1099078x

Newsletters

Spectrum Autism Research News	https://www.spectrumnews.org/
Disability Scoop	https://www.disabilityscoop.com
Autism Research Podcasts	https://journals.sagepub.com/page/aut/podcasts
Autism Parenting Magazine	https://www.autismparentingmagazine.com/

Foundations

Organization for Autism Research	https://researchautism.org/
National Autism Center	https://www.nationalautismcenter.org/
Autism Speaks	https://www.autismspeaks.org/
Autism Science Foundation	https://autismsciencefoundation.org/

Autism Research Institute	https://www.autism.org/
Autism Society of America	https://www.autism-society.org/
Simons Foundation for Autism Research	https://www.sfari.org/

Advocacy Groups

Autism New Jersey	https://www.autismnj.org/
Autistic Self Advocacy Network	https://autisticadvocacy.org/
National Autism Association	http://nationalautismassociation.org/
Central NY Chapter of Autism Society of America	https://www.cnyasa.org/
Upstate NY Autism Alliance	http://www.upstatenyautism.org/
Parent to Parent of New York State	http://parenttoparentnys.org/
Autism Society of the Greater Capital Region	https://www.asgcr.org/
Autism Council of Rochester	https://www.theautismcouncil.org/
Autism Up	https://autismup.org/
Asperger Autism Network	https://www.aane.org/
Autism Society of Western New York	https://autismwny.org/
NEXT for Autism	https://www.nextforautism.org/
Specialized Autism Support and Information	https://sasiny.org/
Autism Beacon	http://autismbeacon.com/home
American Autism Association	https://www.myautism.org/

Staff Training

Interdisciplinary Technical Assistance Center on Autism and Developmental Disabilities	https://www.aucd.org/itac/template/training_toolbox.cfm
Ohio Center for Autism and Low Incidence	https://www.ocali.org/

Directory of Individual Providers

Behavior Analysts	http://www.BACB.com
Psychologists, therapists, social workers	https://www.psychologytoday.com/

Diagnosis

CDC	https://www.cdc.gov/ncbddd/autism/screening.html
Autism Speaks Learn the Signs	https://www.autismspeaks.org/learn-signs
Well Child Lens	https://www.wellchildlens.com/video_room/section/process-and-diagnosis
Adult Diagnosis	https://www.autismspeaks.org/expert-opinion/getting-evaluated-autism-adult-where-go-who-see

Early Intervention

NYS Department of Health	http://www1.nyc.gov/site/doh/health/health-topics/early-intervention.page
Early Childhood Direction Centers	http://www.p12.nysed.gov/specialed/techassist/ecdc/home.html
Early Intervention Provider List	http://www.p12.nysed.gov/specialed/techassist/ecdc/home.html

Tool Kits

Autism Speaks Tool Kits by Topic	https://www.autismspeaks.org/adults-22
Organization for Autism Research Tool Kits by Topic	https://researchautism.org/how-we-help/families/resources/

Education

Special Education	http://www.p12.nysed.gov/specialed/autism/
Approved Schools	http://www.p12.nysed.gov/specialed/appschools.html
Transition from Early Intervention to SED (age 3-5 yrs)	https://www.health.ny.gov/community/infants_children/early_intervention/transition/
NYC ASD NEST & Horizon Programs	https://steinhardt.nyu.edu/asdnest/

Treatment Options

Association for Science in Autism Treatment	https://asatonline.org/
Well Child Lens	https://www.wellchildlens.com/video_room/section/therapies
Autism Science Foundation: Beware of non-evidence based treatments	https://autismsciencefoundation.org/what-is-autism/beware-of-non-evidence-based-treatments/
Upstate Family Behavior Analysis Clinic	http://www.upstate.edu/healthcare/providers/location.php?clinicID=1138

Employment

Administration for Community Living	https://acl.gov/programs/youth-transitions/employment
US Department of Labor Office of Disability Employment Policy	https://www.dol.gov/odep/topics/Autism.htm
Integrate Autism Employment Advisors	https://www.integrateadvisors.org/for-employers
Spectrum Careers	https://www.thespectrumcareers.com/
Specialistern	https://specialisterneusa.com/
Career and Employment Options, Inc.	http://www.ceoincworks.com/
Job Path NYC	http://www.jobpathnyc.org/
NYS Adult Career	http://www.acces.nysed.gov/vr

Housing

Autism Speaks Housing Toolkit	https://www.autismspeaks.org/tool-kit/housing-and-residential-supports-tool-kit
OPWDD Housing Options	https://opwdd.ny.gov/opwdd_services_supports/residential_opportunities/housing_options

Special Needs Legal Counsel

Wrights Law	https://www.wrightslaw.com/
Disability Rights New York	https://www.drny.org/

Other

Association for Science in Autism Treatment	https://asatonline.org/for-parents/becoming-a-savvy-consumer/
Autism Watch (Watch Dog)	https://www.autism-watch.org/
US Department of Education on Research	https://www2.ed.gov/rschstat/research/pubs/rigorousvid/index.html
OAR A Parent's Guide to Research	https://researchautism.org/resources/a-parents-guide-to-research/
Interactive Autism Network	https://iancommunity.org/cs/understanding_research/overview
Autism Spectrum News	https://autismspectrumnews.org/
Autism Science Foundation	https://autismsciencefoundation.org/

Advocacy Groups

Autism New Jersey	https://www.autismnj.org/
Autistic Self Advocacy Network	https://autisticadvocacy.org/
National Autism Association	http://nationalautismassociation.org/
Central NY Chapter of Autism Society of America	https://www.cnyasa.org/
Upstate NY Autism Alliance	http://www.upstatenyautism.org/
Parent to Parent of New York State	http://parenttoparentnys.org/
Autism Up	https://autismup.org/
Asperger Autism Network	https://www.aane.org/
NEXT for Autism	https://www.nextforautism.org/
Specialized Autism Support and Information	https://sasiny.org/
Autism Beacon	http://autismbeacon.com/home
American Autism Association	https://www.myautism.org/
Atlas Foundation for Autism	http://www.atlasforautism.org/
Autism Society of North America – North Central Bronx	
The Grace Foundation of New York	https://www.graceofny.org/
New York Families for Autistic Children	https://www.nyfac.org/
Child & Family Support Services, Inc.	https://www.nycfss.org/
My Time, Inc	https://www.mytimeinc.org/
Include NYC	

The Long Island Advocacy Center, Serving Nassau and Suffolk Counties	
Autism Society - Nassau Suffolk	http://www.nsasa.org/
Center for Family Support	https://www.cfsny.org/
Westchester Jewish Community Services	http://www.wjcs.com/
Starbridge	
Parent Network of Western New York	
Autism Spectrum Disorder Family Support Group in St. Lawrence County	
Families Together in New York State	https://www.ftnys.org/
Center for Autism and Related Disabilities (CARD)	https://www.albany.edu/autism
Autism Society of Western New York	https://autismwny.org/
Autism Society of the Greater Capital Region	https://www.asgcr.org/
Autism Council of Rochester	https://www.theautismcouncil.org/
GRASP (The Global and Regional Asperger Syndrome Partnership)	https://grasp.org/
Self-Advocacy New York State (SANYS)	https://sanys.org/