

Survey Questions

1. Below is a list of examples of services that may be used by individuals with autism and their families. Are there any service types that are missing from this list?

- Diagnostic services
- Applied behavioral analysis and other behavioral interventions
- Speech/language therapy and augmentative and alternative communication (AAC) supports
- Assistive technology/medical equipment and associated services and training
- Technology-based, robot-assisted, and artificial intelligence interventions
- Physical therapy
- Occupational therapy and sensory integration therapy
- Academic services and supports
- Mental and behavioral health services and supports
- Self- and family-directed services and supports
- Family/systems navigation
- Caregiver-, family-, and peer-mediated interventions
- Family and peer mentoring supports
- Support, social, and community groups
- Peer-to-peer mentoring and autistic-led support groups
- Caregiver supports and respite care
- In-home caregivers, aides, and nursing care
- Dietary and nutritional support
- Therapies for sleep disorders
- Environmental assessment and modifications
- Transportation vehicle modifications
- Empowerment, education, and advocacy training and services
- Health care transition services
- Employment services, vocational rehabilitation services, job coaching
- Housing support services
- Remote services
- Recreational therapies
- Complementary and alternative interventions (e.g., music, animal-assisted, emotion regulation, and mindfulness therapies)

Dena Gassner	Training on reproductive/sexuality healthcare. Training on personal safety. Understanding variability on medication management for autistic persons. In home support programs for assistance with banking, finance, homemaking, cooking for autistic persons so that they can be employed; this is often taught to people with ID and autism but many never have a single day of life skills training. Even when they do, the work/life balance often exceeds the capacities of persons needing care to work. Assistance with systems navigation with any social care system interacting with autistic person (without fear of punitive actions) such as SSA, VR, Medicare, Medicaid, IRS etc. Parenting support for autistic parents including IEP support in representing their children. Housing supports.
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<p>Alycia Halladay</p>	<p>I don't see pharmacological therapy on here, but it could apply to mental health supports. Or is this non-pharmacological?</p> <p>Also, more remote support/telehealth - this includes navigation but not necessarily services navigation, navigation in understanding the strengths and challenges and where to go and when. For example: Autism Navigator.</p> <p>I'm not sure what "therapies for sleep disorders" mean outside pharmacology and behavior. Behavioral interventions for sleep?</p>
<p>Jenny Mai Phan</p>	<p>Therapies for romantic relationships, sex, and gender dysphoria Mental and behavioral health services and supports (specific to autistic people and autism-related issues)</p>
<p>Hari Srinivasan</p>	<p>1. Proper health care and not diagnostic overshadowing 2. Housing Assistance 3. People who can help guide families around the complex system of services and supports (like guidance counselors) 4. IEP Training for families</p>
<p>Social Security Administration (SSA)</p>	<p>Elopement and wandering supports. See https://jhu.pure.elsevier.com/en/publications/elopement-patterns-and-caregiver-strategies Andersen, A.M., Law, J.K., Marvin, A.R. et al. Elopement Patterns and Caregiver Strategies. <i>J Autism Dev Disord</i> 50, 2053–2063 (2020). https://doi.org/10.1007/s10803-019-03961-x</p>
<p>Substance Abuse and Mental Health Services Administration (SAMHSA)</p>	<p>For "Mental and behavioral health services and supports" might rephrase to say "mental health and substance use disorder services and supports." Health care transition services are noted but might also add primary and specialty care (e.g., pediatrics, adult and child dental health, gastroenterology, vision services) Would add financial management/planning Would add legal services/assistance Transportation vehicle modifications-would add "and medical and nonmedical transportation services" For "Family/systems navigation" would add "and coordination" Add specialized medical equipment and supplies Add wellness services (e.g., tobacco cessation, weight loss, physical fitness, health risk assessments) (Some of this also could fit under other categories above but this could also be a distinct category). Add crisis intervention services</p>

2. What evidence-based services are most beneficial for children and adults with autism?

Alice S. Carter	Evidence-based services that are tailored to meet the needs of children, youth and adults and their families. Services that develop goals collaboratively and are attuned to the affordances (and limitations) in the communities in which families are living.
Dena Gassner	Individualized, child centered training to bridge the gap in knowledge for parents/teachers through the lens of love and acceptance rather than compliance. Ongoing, individually designed supports regardless of intellectual ability focused on functional limitations rather than IQ as a gatekeeper. Elimination of the concept that people can learn and execute certain skills instead of recognizing that many need ongoing supports and not short term lessons.
Alycia Halladay	I would say ABA. And I don't mean the old-school DTT version of ABA. ABA has informed a number of other types of therapies like NBDIs, and almost every early intervention. Most behavioral therapies are based in some sort of ABA.
Jenny Mai Phan	<ul style="list-style-type: none"> • Diagnostic services • Other behavioral interventions • Speech/language therapy and augmentative and alternative communication (AAC) supports • Assistive technology/medical equipment and associated services and training • Physical therapy • Occupational therapy and sensory integration therapy • Academic services and supports • Mental and behavioral health services and supports • Peer-to-peer mentoring and autistic-led support groups • Therapies for sleep disorders • Empowerment, education, and advocacy training and services • Health care transition services • Employment services, vocational rehabilitation services, job coaching • Housing support services • Empowerment, education, and advocacy training and services • Health care transition services • Employment services, vocational rehabilitation services, job coaching • Housing support services • Recreational therapies • Complementary and alternative interventions (e.g., music, animal-assisted, emotion regulation, and mindfulness therapies)
Hari Srinivasan	Biomedical interventions that are individualized and will translate into FDA approved care at mainstream healthcare places.

Social Security Administration (SSA)

This information should be gleaned from the literature and should not be subject to opinion: e.g., <https://pubmed.ncbi.nlm.nih.gov/33449225/> Hume, K., Steinbrenner, J. R., Odom, S. L., Morin, K. L., Nowell, S. W., Tomaszewski, B., Szendrey, S., McIntyre, N. S., Yücesoy-Özkan, S., & Savage, M. N. (2021). Evidence-Based Practices for Children, Youth, and Young Adults with Autism: Third Generation Review. *Journal of autism and developmental disorders*, 51(11), 4013–4032. <https://doi.org/10.1007/s10803-020-04844-2>

3. Which services are widely accessible (i.e., widely available, covered by health insurance, or available at little or no cost)? For those that are not, what are the barriers that need to be addressed to make these services more widely available and accessible?

Alice S. Carter

Traditional ABA services are more widely available for young children than are evidence-based Naturalistic Developmental Behavioral Interventions. Mental health/behavioral health services are very limited across the lifespan but particularly for very young children. Few are even assessed for infant/preschool mental health unless there is obvious and interfering disruptive behavior.

Barriers are training and workforce limitations. Few clinicians are trained to apply evidence-based mental health interventions with autistic children, youth, adults, and their families. This is very unfortunate, as CBT and other evidence-based interventions (for anxiety, executive functioning challenges) do not require a great deal of adaptation and have been shown to be beneficial.

There are also not many options to engage autistic children, youth, and adults in exercise and other healthy individual or family-based recreation that can be stress buffering.

<p>Dena Gassner</p>	<p>Systems navigation is the greatest barrier faced by autistic individuals and families. Administrative burden is extremely punitive and overwhelming. In home homemaker supports, and self care supports are desperately needed across all developmental levels for many autistic individuals. ABA is inconsistent at best in terms of intervention protocols. OT and Speech are often available but are provided too short term-there need to be ongoing access at all ages and developmental levels. Too little PT is provided given the broad range of motor and muscle tone issues (as well as high rates of Co-occurring conditions like EDS). Sexual trauma support and reproductive HC support for autistic persons is not neurodiversity oriented to the unique needs of autistics forming a significant barrier. Dental care inclusive of sedation options without using a hospital setting.</p>
<p>Alycia Halladay</p>	<p>I think AAC needs more research and are widely accessible but they need training to use them. For example, what application on an iPad? How should it be used? Who can support and what training do they need? For most families and individuals, hand them an iPad they need help setting it up and getting the right programs and help using those programs.</p>

<p>Jenny Mai Phan</p>	<p>Which services are widely accessible? • Diagnostic services • Applied behavioral analysis and other behavioral interventions • Speech/language therapy and augmentative and alternative communication (AAC) supports • Assistive technology/medical equipment and associated services and training • Occupational therapy • Self- and family-directed services and supports • Family/systems navigation • Caregiver supports and respite care</p> <p>For those that are not, what are the barriers that need to be addressed to make these services more widely available and accessible? • Augmentative and alternative communication (AAC) supports: Comprehensive and validated sensitivity assessment for communication disabilities are needed. Screeners and "gold standard" single assessment tool can miss some children who would largely benefit in using AAC supports. • Physical therapy: Communicative difficulties or health professionals not understanding autistic patient's needs can result in lack of access to care. If an autistic patient is in pain but cannot effectively communicate source or areas of pain, health professionals may not prescribe PT but instead pain medications. Pain medications put a "bandaid" on the problem. • Sensory integration therapy: This type of therapy is not yet widely offered. There is less awareness for this type of therapy and whether it is covered by insurance or Medicaid. • Mental and behavioral health services and supports: There is still a critical need for MH and BH services targeted for autistic patients. Some or arguably many MH and BH strategies are less effective for autistic patients that normally are effective for other disabled populations. • Therapies for sleep disorders: Little awareness of this type of therapy offered for autistic patients is seen across the U.S. Plenty of studies exist, however, information about sleep therapy for autistic people, especially children continues to lag behind the research. • Complementary and alternative interventions (e.g., music, animal-assisted, emotion regulation, and mindfulness therapies): Many of these types of therapies are not covered by insurance, nor Medicaid in some states. These interventions can be effective for a number of issues autistic people face while waiting for better mental and behavioral health interventions.</p>
<p>Hari Srinivasan</p>	<p>A majority of autism services are \$\$\$ expensive - huge burden on desperate families.</p> <p>ABA, speech and OT is covered by insurance to my knowledge. But no accountability of quality of any of the services - so autism services has become a profit gouging industry.</p>

<p>Centers for Disease Control and Prevention (CDC)</p>	<p>Inclusion of Individuals with ASD in Health Promotion/Disease Prevention Activities. Examples of these activities include: Education and counselling programs that promote physical activity, improve nutrition, or reduce the use of tobacco, alcohol, or drugs; and Blood pressure and cholesterol assessment during annual health exams, and screening for illnesses such as cancer, diabetes, and heart disease. Including people with ASD in these activities begins with identifying and eliminating barriers to their participation. CDC funds two National Programs on Health Promotion for People with Disabilities —the National Center on Health, Physical Activity and Disability (NCHPAD) and Special Olympics—to work with people with mobility limitations (ML) and intellectual disabilities (ID), respectively. These national organizations support the development, implementation, evaluation, and dissemination of non-research activities aimed at: raising knowledge and awareness of the health needs of people with ML and/or ID; developing and disseminating health promotion models, strategies, tools, and health promotion materials; providing training and education to health care professionals; and promoting the adoption of healthy behaviors aimed at reducing health disparities for people with ML and ID.</p>
<p>Social Security Administration (SSA)</p>	<p>Generally, evidence-based therapies are available and covered by health insurance or provided through school districts. See next response box for thoughts on services not widely accessible and barriers.</p>

4. What are some unmet needs for which services do not currently exist (or exist at scale)?

<p>Dena Gassner</p>	<p>See above</p>
<p>Alycia Halladay</p>	<p>There needs to be more training or support for educators rather than only parents. Parents are of course important and amazing but some of the tools that are available to parents need to also be available to educators in different environments. These include aides in the classroom too.</p>

<p>Jenny Mai Phan</p>	<ul style="list-style-type: none"> • Comprehensive sex and sexuality education supports and services: Direct supports and services are needed for autistic people. Currently, pamphlets and online resources are family's go-to for information. If autistic children gain this education in schools, it isn't clear that there is social validity to what they're learning in school. This area of supports and services need to expand across all developmental ages. The unmet needs are that autistic youth and families are faced with questions left unanswered about puberty, growth, development, sex, and sexuality. There are numerous topics under each of these major categories, such as consent, menstrual cycle, gender identity, hygiene, relationships, victimization, etc. The education on these subjects is widely available, but where are the direct supports and services? Is it covered by insurance or Medicaid?
<p>Hari Srinivasan</p>	<p>State Supports also stop as a Phd student (like Hari Srinivasan) as the grad school stipend (barely enough for non-disabled folks) counts as income. But I'm still significantly disabled and will continue to need those supports. I still need a full time 1:1 aide, independent skills living (ILS) services, in home support services (IHSS), behavioral support, cognitive behavior therapy support. Who will pay for these. How can we afford them. Why are we falling through the cracks. We need to fix these cracks. Why are folks like me being punished for entering higher ed.</p>
<p>Centers for Disease Control and Prevention (CDC)</p>	<p>Emergency preparedness People with disabilities, including ASD, are often disproportionately negatively impacted by disasters, yet disability is frequently underrepresented in data used to guide decision-making and resource allocation during public health emergencies. CDC is working with the Association of State and Territorial Health Officials and the National Syndromic Surveillance Program to create diagnostic code-based definitions to identify emergency department visits from people with disabilities. Absent of available demographic information on disability, diagnostic code-based definitions could be used to identify people with disabilities; however, there is no uniform standard for measuring disability using this method. The goal of this project is to build public health capacity to monitor the health and well-being of people with disabilities before, during, and after public health emergencies. This work will have a sustainable impact on national, state, and local response capacity to detect and monitor the health and well-being of people with disabilities during current and future public health emergencies.</p>

**Social Security
Administration (SSA)**

Key concerns are ensuring health insurance and access to medical care for adults, plus issues relating to housing. Again, there is literature out there that discusses such this:

<https://link.springer.com/article/10.1007/s10803-018-3862-9>

<https://pubmed.ncbi.nlm.nih.gov/32671666/>

<https://link.springer.com/article/10.1007/s10488-022-01192-4>