Maryland Strategic Plan for Autism-Related Needs







MARYLAND STRATEGIC PLAN FOR AUTISM-RELATED NEEDS

I am pleased to join Maryland Department of Disabilities Secretary Carol A. Beatty in presenting the inaugural Maryland Strategic Plan for Autism-Related Needs.

In 2020, the Maryland General Assembly passed legislation creating the position of the State Coordinator for Autism Strategy in Maryland. The State Coordinator is housed in the Maryland Department of Disabilities – the only cabinetlevel, cross-disability policy department in the nation. Maryland continues to lead by being among the first to create a statewide strategic plan for autism related-needs.



GOVERNOR WES MOORE

This plan was developed under the leadership of Victoria Rodríguez-Roldán, State Coordinator for State Autism Strategy, in consultation with the Advisory Stakeholder Group for Autism Related Needs. We thank everyone for their contributions to creating this comprehensive 5-year strategic plan that covers many topics, including employment, education, safety, housing, transportation, and community integration.

The strategic plan represents our commitment to helping Marylanders with autism achieve their highest potential and lead fulfilling lives in their communities. The work will rely on collaboration among state and local government, autistic people, families, private organizations, providers, and more—and we're grateful for such dedicated partnership. We sincerely appreciate your support as we work to advance Maryland as a leader in delivering autism-related services and supports. You are helping us build a brighter future for all Marylanders, ensuring we leave no one behind.

GOVERNOR WES MOORE





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Introduction

Background

In 2020, the Maryland General Assembly passed legislation creating the position of the State Coordinator for Autism Strategy in the Maryland Department of Disabilities. The State Coordinator, in consultation with the Advisory Stakeholder Group on Autism-Related Needs (ASGARN), is responsible for creating and implementing a comprehensive state strategic plan on autism related needs. Please see Appendices A and B for the full text of the laws and a list of the ASGARN members who helped in the development of this Autism Strategic Plan.

A NOTE ON LANGUAGE

Within the autism community, members have different ways of referring to themselves. The two most common ways of self-identification are:

- Person-first language ("person with autism") to differentiate the disability from the person, to express that the person is not defined by the disability.
- Identity-first language ("autistic person") to emphasize that autism is an essential part of who they are, and that they do not perceive their autism as being negative.

Out of respect for the differing opinions, this document uses both types of language as equally as possible.

Why this strategic plan is important

Autism – sometimes referred to as autism spectrum disorder - is a neurological and developmental disability that affects how people learn, communicate, behave, and interact with the world. Autism is considered a developmental disability because symptoms typically appear early in life when a child is in the early stages of development, although autism can be diagnosed at any age. As the National Institute of Mental Health (NIMH) notes, "Autism is known as a 'spectrum'... because there is wide variation in the type and severity of symptoms people experience."¹

Another way to understand autism is as part of neurodiversity. Neurodiversity is a term that describes how people's minds work differently.² While the structure and systems of some peoples' minds are set up for a typical way of thinking (referred to as "neurotypical"), people whose minds operate differently may be referred to as "neurodivergent." The term "neurodivergent" may be used to describe people with autism, as well as people with attention deficit hyperactivity disorder (ADHD), obsessive compulsive disorder (OCD), intellectual disabilities, and people with mental differences that have not been diagnosed.³ The idea of neurodivergence is to highlight that people think, process information, communicate, and interact with others in a variety of different ways.

According to data shared by the Centers for Disease Control and Prevention (CDC), 1 in 36 children are diagnosed with autism. Autistic people can be found in every racial, ethnic, and socioeconomic group. Boys are diagnosed with autism 4 times as often as girls. While the rate of autism diagnosis appears to be growing, this may be in part because educators and medical professionals have become better at diagnosing autism. In the past, some autistics may not have received diagnoses or been misdiagnosed as having a different condition.^{4,5} Although awareness and understanding of autism is more common, many people with autism still have challenges in parts of society, including education, employment, healthcare, and other areas discussed in this strategic plan.

How this strategic plan was developed

This strategic plan was developed in consultation with the Advisory Stakeholder Group for Autism-Related Needs (ASGARN) and its subcommittees, which consist of autistic self-advocates, family members of people with autism, healthcare and support service professionals, government officials, and members of the General Assembly, among others.

We also spoke with many stakeholders, including self-advocates, family members, and healthcare providers. We solicited input from individuals from different regions and backgrounds, including rural parts of Maryland, communities of color, and Spanish speaking immigrant communities.

¹ U.S. National Institute of Mental Health (NIMH). (2024, February). Autism Spectrum Disorder. <u>https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd</u>

² Harris, J. (2023, July 5). The mother of neurodiversity: How Judy Singer changed the world. The Guardian. <u>https://www.theguardian.com/</u> world/2023/jul/05/the-mother-of-neurodiversity-how-judy-singer-changed-the-world

³ Price, D. (2022). Unmasking autism: discovering the new faces of neurodiversity (First edition.). Harmony Books.

⁴ U.S. Centers for Disease Control and Prevention. (2023, March 23). Autism Data Visualization Tool. U.S. Department of Health & Human Services. <u>https://www.cdc.gov/ncbddd/autism/data/index.html</u>

⁵ U.S. Centers for Disease Control and Prevention. (2024, May 16). Data and Statistics on Autism Spectrum Disorder. <u>https://www.cdc.gov/autism/data-research/index.html</u>

How this plan is structured

This strategic plan was developed by the State Coordinator, in consultation with ASGARN. This plan sets out guiding principles, objectives, and strategies. This strategic plan is intended as a 5-year plan. After 5 years, it will be reviewed and updated.

- **Guiding principles** are long-term goals that we intend to achieve through this strategic plan.
- Objectives describe in more detail what steps need to be taken to achieve the guiding principles.
- Strategies will guide the activities that are likely to have a widespread, positive impact on stakeholders and contribute to the accomplishment of objectives.

We will also create annual work plans that identify the specific activities, partners, and performance measures necessary to carry out the strategic plan. The work plans will be revised and updated every year.

- Activities are the specific actions that will be taken to carry out our strategies.
- Partners are the state and local agencies, providers, and other stakeholders we will collaborate with to achieve our activities.
- Performance measures are the data used to measure the results of our activities. When possible, we will be reviewing existing data to help us establish performance measures. In other cases, we may have to create new data tools to collect data that was not previously available.

Vision Statement

We envision a Maryland where people on the autism spectrum as well as their loved ones, families and caregivers experience a high quality of life by possessing the tools to lead their own lives up to their highest potential.

Mission Statement

Improving the quality of life of Marylanders on the autism spectrum as well as their families, caregivers and loved ones by ensuring and promoting opportunity, access and choice so that they can lead healthy, fulfilling and self-directed lives as integral parts of our communities.



GUIDING PRINCIPLE 1

People with autism live and thrive in their chosen communities.





Education

There are several federal and state laws that are intended to support education for students with disabilities from birth through high school graduation or transition at age 21. One law is the Individuals with Disabilities Education Act (IDEA) that requires all children receive a free and appropriate education in the least restrictive environment (LRE). The IDEA sets out requirements regarding special education services and the creation of Individualized Education Programs (IEPs). Additionally, Section 504 of the Rehabilitation Act prohibits discrimination against individuals with disabilities in programs that receive Federal funding, including public schools. Under this law, students may receive accommodations through "504 plans" if they need in-school supports other than, or in addition to, the special education supports and services included in an IEP. It is important to note that not all autistic students have an IEP or 504 Plan. This could be because the school is unaware that the student has a disability, or because it has been determined that the student can participate in education without special education or other accommodations.

The Maryland State Department of Education (MSDE), in collaboration with many partners and stakeholders, is in the process of implementing the Blueprint for Maryland's Future (Blueprint), which is a sweeping, multi-year plan to improve the quality of education for all children in Maryland, especially those who have been historically underserved. A key goal of the Blueprint is that students, with or without disabilities, will exit school ready for college and/or a career. Ideally, students with autism, whether or not they have IEP and 504 plans, will benefit from these changes. Additionally, as part of the Blueprint, the Maryland State Department of Education (MSDE) created a Special Education Workgroup that has been meeting regularly to discuss and refine recommendations to improve special education in schools.⁶

Students who receive special education services under the IDEA while the student remains enrolled in high school are no longer eligible to receive the IDEA services when they leave high school (no later than the school year in which the student turns 21). For students attending post-secondary education after they graduate, age out at age 21, or who attend

⁶ MD State Department of Education. "Special Education Workgroup - Blueprint." *Blueprint for Maryland's Future*, MD State Department of Education, 17 Aug. 2023, <u>https://blueprint.marylandpublicschools.org/special-education-workgroup</u>.

when they are older, reasonable accommodations needed to access their education are made under the Americans with Disabilities Act (ADA). These requests are handled by the college or program they attend, not the local school system.

According to recent data from MSDE, about 12% of K-12 students in Maryland's public schools are identified as having a disability; of the students identified as having a disability, 14% of these students are autistic. In the 2021-2022 school year, 69.3% of students with disabilities receiving special education services graduated within 4 years (compared to 86.3% for all students) and 73.0% graduated within 5 years (compared to 89.0% for all students). Although graduation rates for students with disabilities have been trending up, there remains a gap between the graduation rates for these students in comparison to all students. The dropout rate for K-12 students with disabilities remains slightly higher than for all students (10.8% compared to 8.3% in the 2021-2022 school year). Additionally, within the class of 2020, fewer students with disabilities were enrolled in college within 12 months after graduation than their nondisabled peers (35% versus 63%). Work continues to close the outcomes gaps for students with disabilities to the greatest extent possible.⁷

Education outcomes for all students with autism can be improved by ensuring:

Autistic students and their families are aware of, and able to participate in, the Blueprint for Maryland's Future opportunities for family and student input and engagement

activities. Maryland Blueprint for Success includes a focus on addressing many of the concerns identified by the autism community regarding special education, including the need for more special education teachers, additional resources and support, and improving the consistency and quality of IEP and transition plans. The Blueprint's Special Education Workgroup has held regular public meetings to discuss and refine recommendations and priorities, and includes strong representation from the autism community.⁸ It is important that as this work continues, students with autism and their families are aware of the progress and that their perspectives continue to be included. This work includes a focus on increasing the number of students exiting high school with a diploma. Schools will need to ensure that autistic students and their families have the information necessary to make informed decisions regarding pursuing a high school diploma versus a certificate of program completion as well as the impact of exiting school prior to age 21 on accessing services and supports available to eligible individuals through the Developmental Disabilities Administration.

 K-12 students with autism are served safely and effectively in the least restrictive environment and most integrated setting possible. As noted above, the purpose of the

⁷ MD early intervention and special education services. *Census data & related tables*. (2023). MD State Department of Education. <u>https://www.marylandpublicschools.org/about/Documents/DCAA/SSP/20222023Student/2023DEISESCensusPublication.pdf</u>

Collins, D., Haislet, C., & Morrison, B. (n.d.). (publication). *Data Deep Dive: Students with Disabilities*. MD State Department of Education. https://marylandpublicschools.org/stateboard/Documents/2022/0927/DataDeepDiveStudentsWithDisabilities.pdf

Collins, D., Haislet, C., & Morrison, B. (n.d.). (publication). *Data Deep Dive: Students with Disabilities Pt II*. MD State Department of Education. <u>https://marylandpublicschools.org/stateboard/Documents/2023/0228/DeepDiveStudentsWithDisabilitiesPart2.pdf</u>

⁸ The Blueprint Special Education Workgroup meetings are live streamed. As of the drafting of this document, all meeting materials and information can be found online at https://blueprint.marylandpublicschools.org/special-education-workgroup.



IDEA is to ensure that students with disabilities, including autistic students, receive supports so that they may be educated in the least restrictive environment (LRE) and, to the extent possible, alongside their peers who do not have disabilities. Compared to other states, Maryland historically has had a high rate of educating students with disabilities in segregated settings. The rate of including students with disabilities in general education classrooms has increased over time in Maryland, but it is important that progress be shared equally among students in different underserved communities and across all of Maryland's schools.⁹

- Autistic students exiting school with a certificate of program completion will be able to demonstrate readiness to participate in post-secondary education, careers, or the community. Students who exit high school with a certificate of program completion have historically had fewer post-secondary options. However, to improve post-secondary opportunities, MSDE has been implementing what are known as "endorsements." An endorsement for high school students is a recognition or note added to their diploma or certificate of program completion that shows the student has abilities and met standards in the areas of college, community and career readiness. The endorsement highlights the student's skills and knowledge, making them more meaningful and competitive for postsecondary opportunities and careers. It is important that students with autism and their families know they have a right to discuss these options during the transition portion of the IEP meetings, beginning at age 14.
- Students with autism have meaningful transition plans and access to transition resources that will link them to post-secondary education, career, and/or post-school services. It is critical that students begin planning for the transition from school into post-secondary opportunities well before the student exits high school. In Maryland, for students receiving special education services, transition planning is a required part of the IEP and begins at age 14. Autistic students and their families also need to be able to plan for their postschool transition even if the student does not have an IEP. Such planning requires access to information regarding resources, services, and opportunities after high school.
- Autistic students can access the support needed to complete post-secondary education programs. As noted above, supports for students with disabilities attending post-secondary education falls under the ADA, not IDEA. Students must request reasonable accommodations, which typically involves providing documentation demonstrating why they need the accommodations. Further, the accommodations they receive in post-secondary education are not necessarily required to be the same as what the student received under the IDEA. There is widespread variation in what colleges and universities will accept as documentation and in what reasonable accommodations they provide. As the number of autistic students on post-secondary campuses increases, it is critical to ensure that students have access to consistent and effective supports needed for successful graduation. It is

⁹ According to 2022-23 data among the 50 states and DC, Maryland's combined rate of LRE A (serving students with disabilities in regular classrooms for 80% or more of the day) and LRE B (40–79% of the day in regular classrooms) is 81.46%, ranking it 41st; rate of LRE C (less than 40% of the day in regular classrooms) is 11.34%, 19th highest in the country; and has the 6th highest rate of placing students with disabilities in separate (public and nonpublic) schools (5.54%). Source is: Maryland early intervention and special education services. *Census data & related tables*. (2023). MD State Department of Education. https://www.marylandpublicschools.org/about/Documents/

also important that students with autism who did not have an IEP or 504 plan in the K-12 system may still be able to request ADA reasonable accommodations in their post-secondary program. Ensuring that students request copies of any disability related documentation prior to school exit and understand the importance of accessing the services of college Disability Support Services is critical to their postsecondary education success.

Students with autism who are not eligible for special education services have access to intervention and supports that ensure their academic success. It is important to recognize that not all autistic students qualify for or have special education services. More should be done to capture and share data regarding autistic children and students outside of special education to ensure their needs and concerns are being recognized and met.

OBJECTIVES

- OBJECTIVE 1: Support implementation and awareness of recommendations of the Blueprint for Maryland's Future and the Special Education Workgroup that will benefit students with autism.
 - Strategy 1.1: Engage with individuals and organizations representing the autism community currently participating in Blueprint resources in order to expand participation in and knowledge of the system changes underway in the public school systems.



- **Strategy 1.2:** Collaborate with MSDE and other key partners to develop resources for autistic students and their families to help them more effectively benefit from the changes underway because of the Blueprint process.
- OBJECTIVE 2: Promote efforts to ensure autistic students receive the supports they need to receive equal access to education in least restrictive environments (LRE) to the greatest extent possible.
 - **Strategy 2.1:** Partner with MSDE and Local Education Agencies to obtain data on the education of students with autism in LREs, to discuss recommendations for additional policies and initiatives, and publicize progress, updates and information regarding autistic students and LRE.
 - **Strategy 2.2:** Improve collection and availability of data on autistic students who are receiving 504 plans and increase families' knowledge and awareness of the processes to ensure students' rights are protected.
- ► **OBJECTIVE 3:** Increase the number of students with autism exiting school who are ready for college, careers, and community life and prepared for the transition to post-secondary life.
 - **Strategy 3.1:** Support MSDE's efforts to implement endorsements in the areas of college, career and community for students exiting school with certificates of program completion.



- Strategy 3.2: Improve the career and college readiness capacity of autistic students and their families through development of resources targeted for critical milestones, including starting early intervention, pre-k and K-12 schooling, starting the Individualized Family Service Plan, IEP, or 504 process, and preparing to graduate from or exit school.
- **Strategy 3.3:** Support efforts to develop resource tools to improve connections to postschool services for students with autism who did not have IEPs or 504 plans.
- ► **OBJECTIVE 4:** Increase the capacity of colleges, universities, and other post-graduate programs to support autistic students to graduate/complete the programs successfully.
 - **Strategy 4.1:** Examine state and national efforts to identify strategies to determine ways Maryland can improve access to disability support services and accommodations at college, universities and post-graduate programs.
 - **Strategy 4.2:** Work with institutions and key partners to measure, improve and increase successful outcomes for post-graduate students with autism.





Employment

Through law and policy, Maryland has set expectations that people with disabilities, including those with autism, should have the choice and opportunity to work in individualized, competitive, and integrated jobs while receiving the same pay and benefits as their nondisabled coworkers. In addition to other initiatives, **Maryland has taken major steps to help people with disabilities access the competitive workforce, including**:

- ▶ Becoming the second state in the country to prohibit paying people with disabilities less than minimum wage;¹⁰
- ► Creating a Medicaid Buy-In (the Employed Individuals with Disabilities program) that allows individuals to increase their earnings without loss of benefits¹¹; and
- Becoming an Employment First state, which is a national systems-change framework centered on the idea that all individuals with disabilities are capable of full participation in competitive, integrated employment and community life. Under the Employment First approach, community-based, integrated employment is to be the first option for services for youth and adults with significant disabilities.¹² As part of this Employment First approach, Maryland has incorporated employment supports and job coaching in many of its home- and community-based programs for people with disabilities.¹³

More work needs to be done to support employment opportunities for people with autism. Specific state-level data on unemployment and underemployment rates in the autism community is not available. Based on national data, and given that the employment rates for all Marylanders with disabilities significantly lag behind that of their peers without disabilities, it is very likely that employment rates for autistic people in Maryland is low as

¹⁰ Individuals With Disabilities - Minimum Wage and Community Integration (Ken Capone Equal Employment Act), (2021). MD. Health - General Code Ann. § 7-1012 (2021) <u>https://mgaleg.maryland.gov/mgawebsite/Legislation/Details/SB0417?ys=2016rs</u>

¹¹ MD Department of Health. (n.d.). Employed Individuals with Disabilities program. https://health.maryland.gov/mmcp/eid/Pages/Home.aspx

¹² Gingerich J. (n.d.). Employment First [Fact sheet]. MD Department of Disabilities. <u>https://mdod.maryland.gov/employment/Pages/employment-first.aspx</u>

¹³ MD Department of Health (n.d.). Employment First. https://health.maryland.gov/dda/Pages/employment.aspx



well.¹⁴ According to a 2021 study published in the National Library of Medicine, autistic people have a 40% unemployment rate.¹⁵ Additionally, the Autism Society reports that up to 85% of autistic people with a college degree are unemployed or underemployed.¹⁶

Employment outcomes for Marylanders with autism could be improved by ensuring:

- There is an accurate understanding of the number of job seekers and workers with autism in Maryland. To identify the barriers to finding or keeping jobs that autistic Marylanders experience, it is important to collect data on their employment experiences. While data on disability employment is collected from State and Federal agencies, we need to collect more Maryland data that is autism specific. This information will help us make better policy decisions that can help job seekers and workers with autism.
- Dob seekers with autism have access to appropriate vocational programs, career counseling, and placement services. While some job seekers with autism may be able to access vocational programs through the Division of Rehabilitation Services (DORS), others will have to seek alternative programs and services to assist with job counseling and placement. DORS receives funding that requires it serve people with the most significant disability-related needs first, which has resulted in lengthy wait lists for job seekers who require lower-intensity supports. It is critical that job seekers who are not eligible for DORS programs, or cannot immediately access them, be able to use other resources to assist in finding work. It is important that autistic people be able to access other resources, such as American Job Centers, which provide free assistance and training to job seekers. Some people with autism may experience challenges with communication or executive functioning and may require assistance from staff who are knowledgeable about autism-related needs.
- Autistic workers have access to inclusive and supportive workplaces in both the private and public sector. There is a growing awareness among employers of the benefits of having diverse workplaces that include people with autism. Many of the effective strategies that support their recruitment, onboarding, and long-term success in the workplace go beyond legal requirements for reasonable accommodations. Many of these supports are not costly, but rather are modifications to workplace culture that could make the working environment more inviting for all workers.¹⁷ Training and outreach for employers and providers must include input and representation from people with autism, including those from diverse and underserved backgrounds.
- Workers with autism understand their rights and support needs in the workplace. Laws such as Title I of the federal Americans with Disabilities Act (ADA) and Title 20 of Maryland state

¹⁴ As of 2022, the unemployment rate of Marylanders with disabilities ages 21-64 is around 49.9% per the data from Disability Statistics. K. Lisa Yang and Hock E. Tan Institute on Employment and Disability. (n.d.). *Disability statistics*. Cornell University. <u>www.disabilitystatistics.org/</u>

¹⁵ Ohl, A., Grice Sheff, M., Small, S., Nguyen, J., Paskor, K., & Zanjirian, A. (2017). Predictors of employment status among adults with Autism Spectrum Disorder. Work, 56(2), 345–355. https://doi.org/10.3233/wor-172492

¹⁶ Smith, S. (n.d.). Employment. Autism Society. https://autismsociety.org/employment/#:~:text=85%25

¹⁷ Employer Assistance and Resource Network on Disability Inclusion. (n.d.). Management, Peer Training and Mentoring. Askearn.org; Employer Assistance and Resource Network on Disability Inclusion. <u>https://askearn.org/page/management-peer-training-and-mentoring</u>

law require that many employers provide accommodations to individuals with disabilities in the workplace.¹⁸ It is important that job seekers and autistic workers know their rights in the workplace, including how to request reasonable accommodations. Additionally, for workers with autism who require assistive technology (AT), it is critical for employers and their workers to be aware of what types of AT would be best suited to support them in their work and where to find it.

OBJECTIVES

- OBJECTIVE 1: Develop data-driven policy recommendations to help improve employment outcomes for Marylanders with autism.
 - **Strategy 1.1:** Review and expand the collection of data on rates of employment and employment experiences of autistic Marylanders.
 - Strategy 1.2: Use data to identify possible barriers to integrated, competitive employment for autistic Marylanders.



- ▶ **OBJECTIVE 2:** Support state programs and initiatives that promote employment for people with disabilities, including people with autism.
 - **Strategy 2.1:** Partner with state, local partners, and schools that provide vocational and career training and services to ensure that autistic people can access and benefit from these services.
 - **Strategy 2.2:** Identify best practices and opportunities to support innovation, expansion of training, and programs beyond those funded by DORS that result in increased employment outcomes for the broad cross section of the population for those not eligible for existing services.
- OBJECTIVE 3: Support and expand initiatives that encourage the hiring and inclusion of autistic people in the workplace.
 - Strategy 3.1: Identify best practices that promote the hiring of people with autism.
 - **Strategy 3.2:** Using a coordinated strategy, educate employers about the benefits and best practices of hiring, managing, and working with employees with autism and facilitate employer access to the broad array of candidates that best meet their hiring needs.
 - **Strategy 3.3:** Develop resources to educate autistic workers about their rights in the workplace, including reasonable accommodations and privacy regarding their personal health information.
 - **Strategy 3.4:** Coordinate efforts to ensure workers with autism have access to appropriate assistive technologies in the workplace.

¹⁸ MD Department of Disabilities. (n.d.). Accommodations [Fact sheet]. <u>https://mdod.maryland.gov/employment/Documents/</u> <u>Accommodations.pdf</u>

HOUSING



Housing

Note that this section discusses objectives and strategies to support autistic individuals' access to affordable, accessible rental homes or homeownership. Objectives and strategies related to in-home supports and services, which may be critical to assist some individuals remain in the community, are discussed in the Community Integration section under Guiding Principle 3.

Autistic people face similar barriers to housing that are experienced by the larger disability community. These barriers include difficulties in finding housing that is affordable and accessible.

One of the biggest barriers is the lack of affordable housing. A study conducted by the Urban Institute in 2021 observed that the United States is experiencing the worst shortage of affordable housing in a generation, and that people with disabilities are particularly hard-hit by this shortage. According to data provided as part of this study, 22% of people with disabilities have what is considered "extremely low" incomes, as defined by the U.S. Department of Housing and Urban Development. While the federal government provides funding for housing and rental assistance, there are not enough resources to support everyone who needs help. The study noted that, nationally, 18 million people with disabilities who are eligible for federal housing assistance based on income are not receiving this assistance – either because they are unaware of their eligibility or because there are not enough subsidies available in communities to serve everyone who is eligible.¹⁹ Additionally, for some people with extremely low (or no) income, the subsidies still may not be enough to help them afford housing in their community. Maryland provides rental assistance and incentives to create affordable housing.²⁰ However, Maryland ranks as one of the most

¹⁹ Popkin, S. J., Hermans, A., Oneto, A. D., Farrell, L., Connery, M., & Cannington, A. (2022). *People with disabilities living in the US face urgent barriers to housing*. Urban Institute. <u>https://www.urban.org/sites/default/files/2022-10/People%20with%20Disabilities%20Living%20in%20 the%20US%20Face%20Urgent%20Barriers%20to%20Housing_0.pdf</u>

²⁰ MD Department of Housing & Community Development. (n.d.). DHCD programs. <u>https://dhcd.maryland.gov/Pages/About/DHCD-</u> <u>Programs.aspx</u>



expensive states for renters²¹ and the housing market that has been, overall, steadily growing more expensive,²² which makes providing enough affordable housing a challenge.

Additionally, autistic people may also require homes that are accessible or have modifications to accommodate physical, sensory, or cognitive needs. State and federal laws set out requirements for when landlords must provide reasonable accommodations to ensure that renters with disabilities can access housing.²³ Additionally, Maryland offers programs that assist with assessing homes for accessibility or helping to purchase equipment to modify homes.²⁴

Housing access for people with autism would be improved by ensuring:

- There is an accurate understanding of housing needs of people with autism in Maryland. To identify the barriers to housing, it is important to review existing data and collect additional information on autistic peoples' housing access. While data on disability and housing is collected from state and federal agencies, we need to collect more Maryland data that is autism-specific. This information will help us connect autistic people with existing resources and identify gaps in housing options for people in different communities.
- Autistic people are aware of and can access housing subsidies or housing-related assistance programs. People with autism who have lower incomes may benefit from programs that offer subsidies for rent or utilities. There are also programs, some specifically for people with disabilities as well as homeownership supports available to anyone, that could benefit autistic people. As noted above, some of these programs may not be able to serve everyone who needs support. It is important that the autism community remain represented in efforts to expand the capacity of assistance programs to serve more people with disabilities.
- People with autism have access to accessible housing and autism-specific housing modifications. Some people with autism have co-occurring disabilities, such as mobility challenges, that require physically accessible housing. Additionally, some autistic people may require environmental adaptations to housing such as adjustment to lighting or sound dampening. It is important for autistic people to know about the types of accommodations that would assist them in their home and have access to these supports. For instance, the Maryland Assistive Technology Program (MDTAP) maintains a home modifications directory that provides information about home modifications, funding sources, and loan programs.²⁵

23 Maryland Inclusive Housing (MIH). (2022, December 2). Know your rights. <u>https://mih-inc.org/housing-info/laws-providing-housing-protections-for-people-with-disabilities/#:~:text=People%20with%20disabilities%20are%20artitled</u>

25 MD Technology Assistance Program. (n.d.). Home modifications directory. MD Department of Disabilities. https://mdod.maryland.gov/mdtap/Pages/Home-Modifications-Directory.aspx

²¹ Jones, J. (2023, November 20). U.S. cities with the highest rent prices. Construction Coverage. https://constructioncoverage.com/research/ cities-with-the-most-expensive-rents

²² LaPonsie, M. (2024, April 18). Maryland housing market 2024: Trends & house prices (C. Jennings, Ed.). Forbes Media LLC. https://www.forbes.com/advisor/mortgages/real-estate/maryland-housing-market

²⁴ MD Technology Assistance Program. (n.d.). *Home modifications directory*. MD Department of Disabilities. https://mdod.maryland.gov/mdtap/Pages/Home-Modifications-Directory.aspx



Autistic people understand their rights and obligations when renting or buying homes. It is important that people with autism are aware of their legal rights, such as their right to request accommodations when renting or other rights under landlord-tenant law in Maryland. It is also important that autistic people have access to plain language explanations of legal housing documents, such as leases or mortgage contracts.

OBJECTIVES

- OBJECTIVE 1: Promote the ability of people with autism to rent or buy homes in their chosen communities.
 - **Strategy 1.1:** Collect and review data on autistic people's housing needs.
 - **Strategy 1.2:** Ensure that renters with autism are aware of housing subsidy and rental assistance programs.
 - **Strategy 1.3:** Ensure that homebuyers with autism are aware of disability-specific and general homeownership assistance programs.
- OBJECTIVE 2: Promote awareness of and access to accessible housing, home modifications, and assistive technology that supports independent living.



- **Strategy 2.1:** Participate in outreach efforts that educate landlords and renters with autism to ensure awareness of legal rights regarding reasonable accommodations in rental homes.
- **Strategy 2.2:** Promote initiatives that help autistic people evaluate, identify and fund home modifications and assistive technology that supports independent living.
- OBJECTIVE 3: Expand on efforts to educate autistic people about their legal rights and obligations when renting or buying homes.
 - **Strategy 3.1:** Collaborate with initiatives that educate renters about their rights to ensure the materials are available to autistic renters and include information on disability-related protections.
 - **Strategy 3.2:** Collaborate with initiatives that educate individuals about financial and legal responsibilities of homeownership to ensure the materials are accessible.



Transportation

People with autism have similar challenges in accessing transportation as the larger disability community. Autistic people who can drive must navigate the process of getting and maintaining a driver's license through the Motor Vehicles Administration (MVA). People with autism who have not learned to drive, cannot obtain a driver's license, or cannot afford to purchase a car must rely on public transportation, getting rides with friends and family or pay for taxis or rideshare services. Some people with autism, including those with physical and sensory disabilities, may also need to modify their vehicles.

Maryland is considered by many to have a relatively robust public transportation system within certain regions of the state. For instance, the Maryland Transit Administration (MTA) is one of the largest public transit systems in the country that includes buses, light rail, subways, commuter trains, and paratransit for people with disabilities.²⁶ However interconnectivity of Maryland's various transportation systems remains a significant challenge. Each county has their own public transit system, which complicates cross-state travel and is an issue of ongoing concern in the larger disability community. Additionally, work continues to ensure that the different systems are reliable and on time.

Maryland has taken steps to assist drivers with disabilities, which may benefit drivers with autism. The Maryland Motor Vehicle Administration (MVA) provides different options and special accommodations to assist drivers with disabilities. Some of these options include, but are not limited to, extra time for written or oral tests, plain language driver manuals and videos, and audio enhancements.²⁷

²⁶ MD Department of Transportation. (n.d.). About us. MD Transit Administration. https://www.mta.maryland.gov/about

²⁷ Motor Vehicle Administration. (2024, February 5). Maryland learner's permit exam now available in 17 languages including American Sign Language [Press release]. MD Department of Transportation. <u>https://mva.maryland.gov/Pages/NewsDetails2.aspx?NR=2024484;</u> Tuss, A. (2024, February 21). *Maryland simplifies language of learner's permit test*. NBC4 Washington. <u>https://www.nbcwashington.com/news/local/transportation/maryland-simplifies-language-of-learners-permit-test/3549566/</u>

Transportation access for Marylanders with autism could be improved by ensuring:

- There is an accurate understanding of transportation and travel needs of people with autism in Maryland. The Maryland Department of Transportation (MDOT) does not collect information on autistic consumers of transportation or paratransit services. To identify the barriers to transportation and travel, it is important to review existing data and collect additional information on people with autism's transportation access and experiences. This information will help us connect autistic people with existing resources and identify gaps in transportation options for people in different communities.
- Autistic people can access public transportation. Individuals with disabilities, including people with autism, can learn to use public transportation through travel training, a short-term comprehensive one-to-one instruction provided by qualified personnel. Travel training teaches the skills and techniques necessary to negotiate public transportation in a safe and independent manner. The instruction is individualized to the person's needs and abilities and is taught in the natural environments in which the individual plans to travel. Travel skills are learned while following a particular route, generally to school or a work site, using the safest, most direct route. Maryland provides travel training through various state agencies, local and non-profit organizations. Maryland continues to work to increase funding, resources, and partnerships to expand travel training programs to even more organizations throughout the state.
- People with autism have transportation options in areas with limited public transportation, particularly in rural areas. In some areas of Maryland, especially in rural areas, public transportation is limited or unavailable. It is important to support efforts to make public transportation and paratransit services more widely available in underserved areas. It may also be helpful to explore or expand on initiatives to develop alternative options for transportation in these areas, such as subsidizing ride sharing programs.
- Autistic drivers are aware of resources that support drivers with disabilities. The MVA has developed plain language and video resources that can be useful to autistic people who are studying for and taking their driver's test. Additionally, some autistic drivers, including those with co-occurring disabilities affecting mobility or visual processing, may benefit from adaptations to their vehicles that will help them drive. These adaptations could include special mirrors or different ways of controlling the car pedals. It is important that drivers with autism know about resources provided through the Maryland Assistive Technology Program (MDTAP) and the Assistive Technology Loan Program that can help them learn about, evaluate, and purchase adaptations.

OBJECTIVES

- Objective 1: Promote the ability of autistic people to travel as independently as possible.
 - Strategy 1.1: Collect and review data on people with autism's transportation needs, particularly access to and use of public transportation.
 - **Strategy 1.2:** Encourage the use of autism-literate travel training.
- Objective 2: Expand access of non-drivers with autism to transportation options.
 - **Strategy 2.1:** Support efforts that promote expansion and coordination of public transportation systems (including paratransit), particularly in rural areas.
 - **Strategy 2.2.** Identify and support alternative transportation strategies in areas with limited public transportation options.
- Objective 3: Support autistic drivers' access to appropriate driving materials and adapted vehicles.
 - **Strategy 3.1:** Promote continued awareness of accessible drivers' education, licensing materials, and testing requirements.
 - **Strategy 3.2:** Promote awareness of adapted driving programs, driver training, and vehicle funding options.

GUIDING PRINCIPLE 2 Autistic people and their caregivers are safe and healthy in their homes and communities.



Safety

People with autism face various challenges in the context of disasters, emergencies, or crisis situations. For example, barriers in communication can lead to misunderstandings with first responders, good Samaritans, and law enforcement. Maryland has had a longstanding commitment to improving the safety of autistic individuals, requiring training standards for entry-level law enforcement and every 3 years for officers on how to effectively interact with people with intellectual or developmental disabilities (including people with autism). Starting December 1, 2024, trainings will include issues around wandering and elopement.

Maryland has been transitioning 911 emergency services to "Next Generation 911" (NG911). NG911 technologies allow people to contact emergency services through voice, text, video, or photos.²⁸ These alternative forms of communication make emergency services more accessible to people who have trouble communicating by phone. Additionally, Maryland has been working to expand access to services such as 988 that can respond to emotional health crises that do not require involvement from law enforcement. In 2024, multiple Maryland state agencies began participating in The Link Center Policy Academy, funded by the federal Administration of Community Living (ACL). The purpose of the policy academy is to help make mental health treatment and supports more available to individuals with intellectual and developmental disabilities (including autism), brain injury, and cognitive disabilities.²⁹ Activities related to this work include holding listening sessions with the disability community, developing a strategic plan, and reviewing trainings for mobile crisis unit teams on interacting with people with disabilities, including autistic people.

²⁸ State of Maryland. (n.d.). Maryland 911. https://911.maryland.gov/

²⁹ The Link Center. (2023, December 20). U.S. Administration for Community Living. Supporting Crisis Services to Ensure Optimal Coordination for Children and Adults with Co-Occurring Cognitive Disabilities and Behavioral Health Conditions Policy Academy - Request for Application for State Participation. <u>https://acl.gov/sites/default/files/ATRC/The%20Link%20Center%20Policy%20</u> <u>Academy%20State%20Application_Released%20Dec%202023.pdf</u>

The safety of Marylanders with autism and their families would be supported further by ensuring:

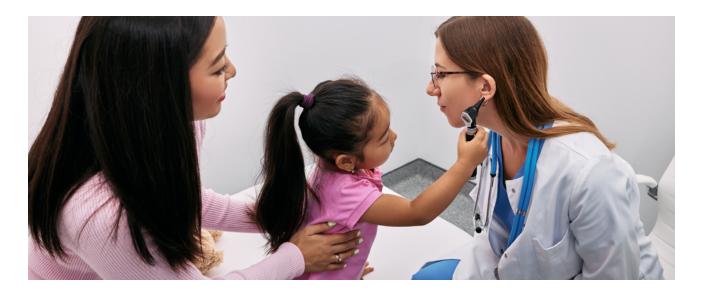
- Public safety professionals are able to interact appropriately with autistic people. It is important that emergency responders such as emergency line operators, 9-1-1 Specialists, fire fighters, emergency medical services personnel and emergency department staff are aware of autism-related needs and communication. To prepare for these interactions, autistic people should be aware of resources that allow them to communicate their needs to first responders, such as creating online or smartphone emergency profiles and options to communicate with 9-1-1 services via text. It is also important that the autism community continue to collaborate with local officials and first responders to develop strategies for responding appropriately to situations when people with autism have eloped or wandered from their homes.
- First responders are knowledgeable about de-escalation strategies which may help them communicate with people with autism during crisis situations. First responders should receive training on safe, non-physical de-escalation strategies which may help prevent poor outcomes during interactions between first responders and autistic people. Autistic people may not feel safe or able to fully communicate during a crisis. Trainings for first responders on de-escalation should be developed in collaboration with people with autism and mental health practitioners.
- Criminal justice professionals who interact with autistic people are knowledgeable about autism-related needs. Court professionals and correctional systems staff should be aware of the unmet needs of autistic people who are court-involved. Unmet needs may include additional support to ensure that people with autism can understand and fully participate in court proceedings. Incarcerated or detained autistic children and adults may need reasonable accommodations, such as continuation of IEPs or additional support for behavioral, communication, sensory, or other autism-related needs.
- People with autism and their caregivers are supported in preventing and responding to wandering or elopement. According to the CDC, wandering (also called "elopement") is when someone leaves a safe area (such as a home) or a responsible caregiver. These situations are more serious than when someone leaves a safe area for a short period of time and can result in the person being harmed or injured. Children and some adults with disabilities, including autism or intellectual disabilities, have a higher incidence of wandering than their nondisabled peers.³⁰ Caregivers and families must be able to access resources that can assist them in developing plans for preventing or addressing episodes of wandering that keeps the autistic person safe while retaining as much independence as possible. Additionally, programs such as the Maryland Assistive Technology Program (MDTAP) can provide consultations or lend assistive technology devices to people with autism and their families that help them learn about door alarms, location services, and other non-invasive devices to enhance a family's overall safety plan.
- 30 U.S. Centers for Disease Control and Prevention. (2024, May 15) *Wandering (Elopement)* [Fact sheet]. <u>https://www.cdc.gov/child-development/disability-safety/wandering.html</u>

- Autistic people and their families can access crisis intervention experts during behavioral health crises. It is important that autistic people and their families are aware of alternatives to contacting 9-1-1 when a person with autism is having a behavioral health crisis. These alternatives include calling 988 (the crisis hotline), a mobile crisis unit, or visiting walk-in stabilization centers. In turn, it is important that the individuals staffing these services are specifically trained in autism-related needs.
- People with autism can report crimes and access protections against abuse. It is important that autistic children and adults recognize situations that are unsafe or abusive and know where to seek help. Families and mandatory reporters should be able to recognize the signs and symptoms of abuse or neglect to help protect people with autism, including people with communication or cognitive disabilities that may prevent them from reporting abuse directly.

OBJECTIVES

- OBJECTIVE 1: Expand training for first responders and other emergency professionals on autism-related needs.
 - **Strategy 1.1:** Collaborate with current initiatives that educate first responders about developmental disabilities and reasonable accommodations.
 - **Strategy 1.2:** Expand trainings to other emergency professionals, such as emergency room staff and 9-1-1 specialists.
- ► **OBJECTIVE 2:** Ensure that court and correctional services staff have training on developmental disabilities and reasonable accommodations.
 - **Strategy 2.1:** Collaborate and expand initiatives that educate court professionals and corrections services staff on developmental disabilities and reasonable accommodations for autistic people that are court involved.
 - **Strategy 2.2:** Support the training of court professionals and corrections services staff on recognizing unmet needs of people with autism and how to assist or engage supports.
- ► **OBJECTIVE 3:** Increase access to and awareness of resources to prevent or respond to episodes of wandering or elopement.
 - **Strategy 3.1:** Build on safety planning resources for autistic people and their families that address prevention of and response to episodes of wandering.
 - **Strategy 3.2:** Ensure people with autism and their families are aware of, and have access to, assistive technology and other resources that may assist with prevention of episodes of wandering.
- ► **OBJECTIVE 4:** Increase access and build capacity for intervention services for autistic people who are experiencing behavioral health crises.
 - Strategy 4.1: Ensure that autistic people and their families and caregivers are aware of, and can access, 988 and other crisis services.
 - **Strategy 4.2:** Ensure that people with autism and their families and caregivers are aware of, and can access the local mobile and fixed-location crisis units.
 - **Strategy 4.3:** Ensure that providers of crisis services have provided staff training on reasonable accommodations and autism related needs.

SAFETY



Health Care, Identification, and Intervention

All Marylanders deserve access to healthcare that is high-quality, equitable, and accessible. Maryland is working to improve our healthcare system by reviewing current and best practices for healthcare models and developing work groups focused on the complex care needs of people dually diagnosed with intellectual and developmental disabilities and behavioral health needs. The state is also developing policies around telehealth, implementing cultural competencies and bias training, and developing programs with integrated care coordination between physical and mental health care. While this work is ongoing, we strive to improve autistic individuals' access to healthcare systems, diagnostic resources, and health outcomes.

People with autism face challenges that can prevent them from receiving and participating in healthcare in a meaningful way. For children, accessing healthcare can be critical to receiving a diagnosis of autism that would help them access interventions and supports that could have a profoundly positive impact on their development. Examples of these challenges may include, but are not limited to: a lack of providers who are knowledgeable about autism and autism-related needs across the lifespan; difficulties in communication with providers and office staff; and the cost of services or gaps in insurance coverage of services.³¹ Additionally, some people with autism may have other considerations, such as needing transportation to get to appointments, health care facilities that are physically accessible, or healthcare providers that accept Medicaid or specific insurance plans. These challenges are even more significant for autistic individuals who have complex health care needs and who belong to other underserved communities that experience systemic barriers to healthcare.

31 Malik-Soni, N., Shaker, A., Luck, H., Mullin, A. E., Wiley, R. E., Lewis, M. E. S., Fuentes, J., & Frazier, T. W. (2021). Tackling healthcare access barriers for individuals with autism from diagnosis to adulthood. Pediatric Research, 91(5), 1028–1035. PubMed Central. https://doi.org/10.1038/s41390-021-01465-y

Health care outcomes for Marylanders with autism could be improved by ensuring:

- Autism-related treatments are covered and coordinated. People with autism may need a variety of therapies in addition to physical health services, including behavioral health services and allied health services (such as occupational therapy or speech-language therapy). Some autistic patients with complex health needs or who experience challenges with organizing and performing tasks may need additional assistance obtaining health insurance coverage or coordinating their health care.
- There are enough physical, behavioral, and allied health care providers in all communities, including rural communities. In Maryland, 18 of the 24 counties are considered rural. These counties are home to 25% of Maryland residents. As noted by the Maryland State Office of Rural Health Care (SORH), access to health care can be particularly challenging for all people living in rural areas, where people may have fewer health care options due to a lack of providers, transportation and technology barriers.³² For people with autism who may need access to specialized health care services, these limitations can be especially challenging. People in rural areas may have to travel long distances to access care or find that the closest provider is across the border in another state. It is important that we continue to work to identify and support solutions to shortages of providers in underserved communities.
- Children with autism are diagnosed at an early age so they can receive timely supports. Research suggests that providing early intervention and supports for children with autism prior to the start of pre-school (at ages 2 or 3) can have positive long-term effects.³³ General barriers to healthcare access, such as a lack of providers, insurance coverage, transportation, or other resources can prevent children from receiving this diagnosis. A critical step in helping children receive early diagnosis is to ensure that there are enough providers in Maryland who can identify and diagnose autism, and that these providers are available statewide and to people from underserved communities.
- Health care providers are knowledgeable about autism diagnosis and autism-related needs for people of all ages. While autism is often diagnosed when people are young, it is important to understand that autism is a lifespan disability. Health care providers, if properly trained in autism, may be able to help identify autistic adults who were previously undiagnosed. It is also critical that health care providers understand how individuals' treatment needs may change as the person gets older.³⁴
- People with autism's perspectives are included in health care delivery. Including voices of autistic people in health care can help improve awareness of autism-related needs, as well as reduce stigma, bias, and misunderstandings about people with autism. Autistic people can play an important role in health care delivery, including providing education and training about autism for healthcare professionals. It is particularly important to include people with

³² MD State Office of Rural Health. (2024, September 13). *Rural Health*. Office of Population Health Improvement; MD Department of Health. <u>https://health.maryland.gov/pophealth/Pages/Rural-health.aspx</u>

³³ Eunice Kennedy Shriver National Institute of Child Health and Human Development. (2017, January 31). U.S. National Institute of Health. Early intervention for autism. http://www.nichd.nih.gov/

³⁴ Malik-Soni, N., Shaker, A., Luck, H., Mullin, A. E., Wiley, R. E., Lewis, M. E. S., Fuentes, J., & Frazier, T. W. (2021). *Tackling healthcare access barriers for individuals with autism from diagnosis to adulthood. Pediatric Research*, 91(5), 1028–1035. PubMed Central. https://doi.org/10.1038/s41390-021-01465-y

autism who belong to underserved communities that experience barriers to health care (in addition to the barriers faced by autistic people) such as people who identify as LGBTQIA+, immigrants, non-English speakers, and people of color. Additionally, people with autism interested in working in health care careers should be encouraged.

Autistic people are empowered to direct their own health care. It is important for health care providers to understand that people with autism who are not under legal guardianship for medical decisions have the same rights as other patients - including the right to access the same level of care as others, the right to informed consent to or refusal of medical treatments and the right to privacy of health information. People with autism who need additional support in making decisions about health care should have access to supported decision making. Starting in 2022, Maryland requires that people with disabilities, including people with autism, have access to supported decision making when making decisions about health care.³⁵ Both providers and autistic patients should know about supported decision making in health care contexts.

OBJECTIVES

- OBJECTIVE 1: Expand access to diagnostic, physical, behavioral, and allied health providers.
 - **Strategy 1.1:** Identify any specific ongoing coverage or care coordination gaps for autism-related therapies.
 - **Strategy 1.2:** Support initiatives that incentivize health care delivery in rural and underserved communities.
 - **Strategy 1.3:** Support coordination of access to outof-state providers in communities along borders with other states.



- **Strategy 1.4:** Support initiatives that expand the number of providers available to provide diagnoses and early childhood interventions.
- OBJECTIVE 2: Increase knowledge and capacity among healthcare professionals about autism diagnosis and autism-related needs.
 - **Strategy 2.1:** Support development of training, technical assistance, and continuing education curricula focused on autism literacy for all healthcare professions.
 - **Strategy 2.2:** Engage experts and self-advocates from within the autism community to help with educating health care professionals.
 - **Strategy 2.3:** Encourage and support people with autism who are seeking employment in healthcare professions.
- **OBJECTIVE 3:** Support autistic patients' participation in their health care decisions.
 - **Strategy 3.1:** Support education and training for health care professionals about autistic patients' rights to direct their own care and about supported decision making models.
 - **Strategy 3.2:** Ensure patients with autism have access to plain language resources about informed consent about health care treatments and privacy of healthcare information.

³⁵ MD Developmental Disabilities Council. (2022, August). Supported decision-making [Fact sheet]. <u>https://www.md-council.org/</u> wp-content/uploads/2022/08/Supported-Decision-Making-Fact-Sheet.pdf; Disability Rights MD. (n.d.). Supported-decision making resources. <u>https://disabilityrightsmd.org/supported-decision-making/</u>

FAMILY AND CAREGIVER SUPPORTS



Family and Caregiver Supports

As described by the Maryland Commission on Caregiving, caregivers provide a family member, friend or neighbor with supportive care when they are unable to care for themselves. Caregiving may include helping an adult or child with an illness or disability accomplish activities of daily living, such as walking or getting dressed, household chores, or money management. It may also include coordinating outside services, and medical care. Other support includes driving the individual to appointments or visiting regularly with a concern for their personal safety and well-being.³⁶

Looking at national data, it is estimated that 1 in 5 adults (53 million people) are acting as caregivers to people with disabilities, older adults, or people with chronic health conditions. Many caregivers do not get paid for all (or any) of their caregiving activities; it is estimated that if all caregivers received payment for caregiving, the annual value of their work would be \$500 billion. While many caregivers enjoy providing support to loved ones, over time the work required to support another person can have an impact on caregivers' emotional, mental, physical, and/or financial well-being.³⁷

Support for the Families and Caregivers of Marylanders with autism could be improved by ensuring:

Caregivers have a voice in developing relevant policies and resources. In 2023, the Maryland Department of Human Services (DHS) and the Maryland Commission on

36 MD Commission on Caregiving. (n.d.). *Maryland Commission on Caregiving*. MD Department of Human Services. <u>https://dhs.maryland.gov/maryland-commission-caregiving/</u>

³⁷ Utz, R. L. (2022). Caregiver respite: An essential component of home- and community-based long-term care. *Journal of the American Medical Directors Association*, 23(2), 320–321. <u>https://doi.org/10.1016/j.jamda.2021.12.020</u>

FAMILY AND CAREGIVER SUPPORTS

Caregiving in collaboration with the University of Maryland, School of Social Work. released a survey that asked caregivers of adults over age 18 to share what they believe are the priorities for supports and services.³⁸ As of the drafting of this strategic plan, the data is being analyzed. Once this analysis is available, we will use the information to inform further activities and policy recommendations regarding caregivers for people with autism.

- Caregivers have access to the support they need to maintain their physical and mental health. Preventing caregiver fatigue and ensuring that caregivers have the time and resources to care for their own physical and mental well-being has been a longstanding challenge. It is important that caregivers have resources that help them recognize and address signs of stress or fatigue. Caregivers should also have access to assistive technology or home adaptations that can assist with physical tasks, such as helping the person they care for get safely in and out of a bathtub.
- Caregivers have access to childcare and respite care. One critical component of supporting caregivers' physical and emotional well-being is ensuring that they can take breaks from caregiving to focus on their own needs. Childcare programs, as well as before and after school programs, should be accessible to children with autism to the greatest extent possible. Families of both children and adults with autism should have access to respite care as needed. Respite care provides temporary support (typically from a paid worker) for the person with a disability while their caregiver is doing other non-caregiving activities. While respite care may be covered by certain Medicaid home- and community-based programs,³⁹ respite services are often not covered by health insurance and the cost of paying for services may be difficult for some families. Maryland State Government does provide some support for respite care.⁴⁰ Since demand for these resources is high, expanding the capacity of these programs is critical. Additionally, it is necessary to support the paid direct care workforce to ensure that there are enough workers to provide respite care services.

Autistic people and their caregivers are aware of resources which support preparedness to help prevent or respond to crises. It is important that people with autism and their families have resources that can aid in addressing emergencies, such as natural disasters, family conflict, or behavioral health crises - all situations that could be complicated if an individual has communication or cognitive challenges. It is important that autistic people and their families are aware of preparedness activities they can complete prior to a crisis. These strategies may include de-escalation training, developing a safety plan, practicing a communication plan, performing a safety audit at the home, and exploring assistive technology that supports household safety. All these tools should be used to ensure the person with autism and their family members remain safe during emergencies or crises.

³⁸ The Elm. (2023, November 28). 2023 Maryland family caregiving survey. University of Maryland, Baltimore. <u>https://elm.umaryland.edu/announcements/2023/2023-MARYLAND-FAMILY-CAREGIVING-SURVEY.php</u>

³⁹ Developmental Disabilities Administration. (n.d.) Respite Care Services [Fact sheet]. MD Department of Health.

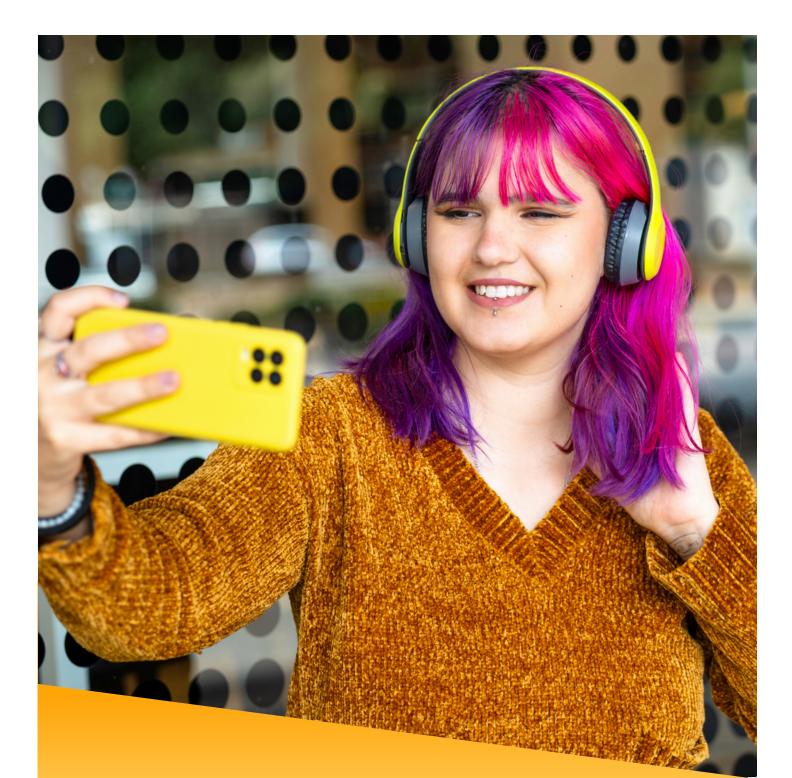
⁴⁰ Office of Adult Services. (n.d.) *Respite Care Program*. MD Department of Human Services. <u>https://dhs.maryland.gov/office-of-adult-services/respite-care-program/</u>



- OBJECTIVE 1: Support physical and behavioral health access and resources for caregivers.
 - Strategy 1.1: Use data gathered from the Family Caregiver survey and other resources to inform future policy recommendations.
 - Strategy 1.2: Partner with MSDE and others to improve availability of inclusive, accessible childcare, including before and after school care.
 - **Strategy 1.3.** Ensure caregivers have access to resources for caregiver self-care and mental health care in the context of caregiving.
 - Strategy 1.4: Ensure caregivers have access to resources regarding the physical health effects of caregiving, including recognizing the physical signs of fatigue.



- **Strategy 1.5:** Ensure caregivers have access to resources, including information about and funding for, assistive technology or home modifications that could help with physical caregiving tasks.
- OBJECTIVE 2: Increase access to and awareness of resources to prevent or react to critical incidents.
 - **Strategy 2.1:** Build on resources for autistic people and their families that assist with emergency preparedness planning, including safety audits of homes and developing communication plans.
 - **Strategy 2.2:** Ensure people with autism and their families are aware of, and have access to, assistive technology that may assist with prevention of or communication during emergencies.



GUIDING PRINCIPLE 3

People with autism lead lives with the greatest degree of self-determination.



Adult Guardianship and Alternatives

Adult guardianship refers to a legal process in which a judge appoints a person, known as a "guardian," to make personal or financial decisions for an adult who is not able to make decisions due to illness or disability. Guardians may be appointed to make decisions about things like paying bills, housing, medical care, clothing, food, education, and everyday needs.⁴¹

Adult guardianship is an issue that affects the entire disability community and is an area of concern within the autism community as well. While guardianship may be necessary for some individuals, it is important that all less restrictive alternatives be considered before someone is placed under guardianship. Maryland offers a number of alternatives to guardianship that can allow an autistic person to receive assistance with some parts of their lives (such as help managing finances) while still remaining independent. Additionally, Maryland offers estate planning options that help ensure a person with autism will have access to financial supports after the death of their parents or caregivers, without needing to place the individual under guardianship.

We can continue to protect the independence of people with autism by ensuring:

Responses to concerns about guardianship are data-driven. In 2021, Maryland received a grant from the federal Administration for Community Living to assess Maryland's guardianship process. This assessment is forthcoming.⁴² When it is released, we will use that information to inform further policy actions.

41 MD Courts. (2018, December). Maryland Guardianship. Maryland Courts. <u>https://www.courts.state.md.us/family/guardianship/</u> <u>courtappointedguardians</u>

MD Courts. (2022, August). Alternatives to Guardianship. Maryland Courts. <u>https://www.courts.state.md.us/legalhelp/family/alternativestoguardianship</u>

⁴² Administration for Community Living. (2021, September 28). New Elder Justice Grants Address APS Training, Guardianship, APS to Community Services Transitions [Press release]. U.S. Department of Health and Human Services. <u>https://acl.gov/news-and-events/</u> <u>announcements/new-elder-justice-grants-address-aps-training-guardianship-aps</u>

Autistic people and their families understand alternatives to establishing legal

guardianship. It is important that adults with autism who may need assistance managing some parts of their lives are aware of the effects and limitations of guardianship and alternatives to guardianship. It is also important that autistic people and their families can access resources that will help them learn about and think through the different options.

- Professionals who interact with people with autism and their families are knowledgeable about alternatives to guardianship. It may be particularly common for families to consider seeking guardianship when their autistic family member is transitioning from childhood to adulthood, or when the autistic family member experiences medical problems. It is important that people who provide advice or services to people with autism and their families, such as professionals working at schools or in health care settings, are aware of alternatives to guardianship. This will help avoid families feeling pressured to seek guardianship for their autistic family member.
- Autistic people and their families have access to affordable resources about estate planning. Financial and estate planning may help establish an autistic person's financial independence and reduce the need for guardianship. It is important that people with autism and their caregivers are aware of and can access these options. As noted by Justice in Aging, some underserved communities, including communities of color and LGBTQIA+ have lower rates of estate planning due to a variety of barriers.⁴³ It is important that people with autism who are members of underserved communities are considered when developing and sharing resources about financial and estate planning.

OBJECTIVES

- OBJECTIVE 1: Collaborate with partners on larger initiatives to educate people with disabilities and their families about guardianship and its alternatives.
 - **Strategy 1.1:** Collect and review data, including forthcoming assessments of the guardianship system conducted by the Administrative Office of the Courts (AOC), that can be used to inform future policies.



- **Strategy 1.2:** Help ensure that information about guardianship and alternatives are shared with and accessible to the autism community.
- **Strategy 1.3:** Support training and curricula for health care, educational, and other service professionals about alternatives to guardianship.
- **Strategy 1.4:** Promote access to and awareness of affordable resources for financial and estate planning.
- **Strategy 1.5:** Support financial and estate planning resources that are intended to support underserved communities.

⁴³ Berchtold, J. (2024, April 16). Justice in Aging. https://justiceinaging.org/alternatives-to-guardianship/





Community Integration

Civil rights laws such as the ADA, as well as Supreme Court decisions such as *Olmstead v. L.C.*, have had a huge impact on supporting people with disabilities' right to live in integrated settings in their community.

To support community integration for people with disabilities, many states, through their Medicaid program, offer home and community-based services (HCBS) options for older adults and people with disabilities who meet financial, medical, and technical eligibility. These HCBS options fund supports necessary for older adults and people with disabilities to maintain independence in their homes and avoid institutional placement.

Maryland operates several home- and community-based service programs. Services across the programs vary and may include personal and attendant care supports, job coaching and employment supports, case management, residential rehabilitation, assistive technology, environmental modifications, and durable medical equipment.⁴⁴ One of these programs, the Autism Waiver, is specifically designed for children with autism up to age 21⁴⁵.

Access to community integration could be supported for Marylanders with autism by ensuring:

Maryland's HCBS system has enough capacity to meet the needs of autistic people of all ages. As noted above, Maryland operates an Autism Waiver that is specifically for children with autism up to age 21. Additionally, there are other waivers that could be available to children or adults with autism if they require intensive supports. However,

⁴⁴ Medicaid. (n.d.) *State Waivers List.* U.S. Centers for Medicare & Medicaid Services. <u>https://www.medicaid.gov/medicaid/section-1115-demo/</u> <u>demonstration-and-waiver-list/index.html?f%5B0%5D=waiver_state_facet%3A541&page=0#content"</u>

⁴⁵ MD State Department of Education. (n.d.). Medicaid Home and Community-Based Services Waiver for Children with Autism Spectrum Disorder (Autism Waiver) [Fact sheet]. <u>https://marylandpublicschools.org/programs/Pages/Special-Education/autismfactsheet.aspx</u>

these programs are not able to serve everyone who applies for them. It is important to examine what resources would be needed to expand the number of autistic people who can receive supports from home- and community-based programs. It is also important to investigate the need for an Autism Waiver for adults with autism.

People with autism are supported in their transition from children to adult services. Children being served by the Autism Waiver or another HCBS waiver for children receive these services until age 21. Once a child reaches 21, although they may continue to need intensive support, they will need to begin receiving supports for adults. In some cases, this involves working with a different state agency, since the Autism Waiver is administered by MSDE while other waivers for adults are administered directly by the Maryland Department of Health (MDH). For many families of children with autism, navigating this transition between children and adult services can be difficult. It is important that we support ongoing efforts to educate families about the requirements for transitioning to adult programs and streamlining the transition process.

There are enough workers to provide services through HCBS programs. There is a national shortage of direct care workers, including direct support professionals (DSPs) who often provide services offered in HCBS programs. The result of this shortage is that sometimes people who qualify for HCBS may experience delays in services or there are frequent changes to the staff providing those services.⁴⁶ This shortage is also impacting Maryland, including HCBS that would be available to people with autism.⁴⁷ The state is exploring ways to increase the larger health care workforce.⁴⁸ It is important that workers who provide HCBS are included in these workforce development efforts.

Autistic people who do not qualify for more intensive HCBS programs have access to supportive resources in their community. Due to program limits or eligibility criteria, many people with autism do not receive services through a Medicaid HCBS program. Additionally, autistic people who receive diagnoses later in life may have trouble getting connected to more formal or intensive services, or not feel that these services are necessary. People with autism who are not receiving HCBS may still benefit from supports for certain aspects of daily living and should have access to community resources. Some of these resources can be developed through work done in support of other strategies, such as the strategies relating to expanding health care access, employment supports, or accessible housing or transportation noted elsewhere in the plan. It is also important to identify other gaps in autism-specific resources in local communities.

⁴⁶ MD Developmental Disabilities Council. (2022). DD Workforce Crisis and the DDA Budget [Fact sheet]. https://www.md-council.org/wp-content/uploads/2022/02/DSP-Fact-Sheet-2022.pdf

⁴⁷ MD Developmental Disabilities Council. (2022). DD Workforce Crisis and the DDA Budget [Fact sheet].

⁴⁸ See, e.g., Pages - Workforce Commission. (2019). Maryland.gov Enterprise Agency Template. <u>https://health.maryland.gov/Pages/</u> Workforce-Commission.aspx

OBJECTIVES

- OBJECTIVE 1: Expand autistic peoples' access to home- and community-based services (HCBS) provided through Medicaid waiver and State Plan services.
 - **Strategy 1.1:** Work with state partners to explore revisions to or expansion of the Autism Waiver.
 - Strategy 1.2: Work with state and external partners to identify the need for and potential pathways to developing more Medicaid homeand community-based service options for adults with autism.
 - Strategy 1.3: Support people with autism in transitions between service systems and settings.



- **Strategy 1.4:** Partner with state agencies to streamline transitions for young adults with autism in the waiver transitioning from K-12 school-based supports to adult service systems.
- **Strategy 1.5:** Support and collaborate on efforts to increase the number of direct support professionals available to provide HCBS.
- ► **OBJECTIVE 2:** Expand community-based resources for people with autism who are not eligible for more intensive home- and community-based services.
 - **Strategy 2.1:** Support efforts to provide autistic people and their families information about supports and resources that they can access in their community.
 - **Strategy 2.2:** Support efforts that promote expansion and coordination of personcentered services that are integrated in the community, particularly in rural areas.
 - **Strategy 2.3:** Support initiatives that raise awareness about identification and autism diagnosis across the lifespan, to ensure adults with previously undiagnosed autism can begin to connect with autism-related supports.



Cultural Competence and Underserved Communities

People with autism may experience additional barriers if they also belong to underserved communities. Throughout this strategic plan, we highlighted areas of specific concern for autistic individuals in underserved communities, such as rural areas, people of color, LGBTQIA+ people, people with complex health needs, older adults, women, and girls, among others. We have also identified specific strategies to reinforce the importance of including underserved communities in all elements of the strategic plan.

As we implement this strategic plan, we will ensure that this plan recognizes:

- People from all communities need access to accurate autism diagnosis. Generally, youths of color have disproportionately low rates of autism diagnosis, which leads to a higher likelihood that they will not receive critical autism-related interventions and therapies at an early age. This underdiagnosis may occur in combination with other barriers to health care experienced by communities of color. Additionally, girls and women also have disproportionately low rates of diagnosis. This could be because they are rated lower on surveys key to the diagnostic process.⁴⁹ According to a federal project collecting data on autism in children, autism is diagnosed in boys almost four times as often as girls.⁵⁰
- Autistic people need access to resources regardless of their location, age, or health needs. Throughout this strategic plan, we noted that people who live in rural regions may experience particular challenges in accessing resources, such as health care or transportation.

⁴⁹ Ratto, A. B., Kenworthy, L., Yerys, B. E., Bascom, J., Wieckowski, A. T., White, S. W., Wallace, G. L., Pugliese, C., Schultz, R. T., Ollendick, T. H., Scarpa, A., Seese, S., Register-Brown, K., Martin, A., & Anthony, L. G. (2018). What About the Girls? Sex-Based Differences in Autistic Traits and Adaptive Skills. *Journal of Autism and Developmental Disorders*, 48(5), 1698–1711. https://doi.org/10.1007/s10803-017-3413-9

⁵⁰ U.S. Centers for Disease Control and Prevention. (2023). Autism prevalence higher, according to data from 11 ADDM communities. In CDC Newsroom. Centers for Disease Control and Prevention [Press release]. https://www.cdc.gov/media/releases/2023/p0323-autism.html

It is important that strategic activities consider that people's autism-related resource needs may change over their lifetime. Additionally, autism-related strategies will need to consider that many people may have or develop other health conditions that must be navigated alongside the person's autism.

- People with autism need access to materials about services and rights in language they can understand. It is important that people with autism who are part of immigrant or non-English speaking communities have access to important materials (such as information about health care, support services, housing, or legal rights) in language and in a manner they can understand. Translations should consider words, tone and cultural context. In July 2024, Governor Moore signed an executive order requiring that the state provide written materials from the state government in plain language.⁵¹ It is critical that as part of this work to make plain language materials available in English, these revised materials are made available in other languages as well.
- Autistic people must be free from discrimination or harassment based on other parts of their identities. Not only is autism a diverse disability, autistic people come from highly diverse backgrounds. Autistic people are in all racial and ethnic groups, all socioeconomic levels, all ages, and all gender expressions. People with autism are more likely to identify as LGBTQIA+.⁵² It is important that people with autism have the same ability to express their identities as non-autistic peers within their communities and are protected from discrimination and harassment on the basis of their identities.

OBJECTIVE

- OBJECTIVE 1: The implementation of the objectives, strategies, and activities of the Autism Strategic Plan is culturally comprehensive and inclusive.
 - **Strategy 1.1:** Ensure policies resulting from this Strategic Plan recognize disparities faced by people in underserved communities in combination with barriers related to autism.
 - **Strategy 1.2:** Ensure materials created as part of this strategic plan are in plain language and non-English languages, as appropriate.
 - Strategy 1.3: Ensure that activities and policies include perspectives of autistic people from diverse backgrounds, communities, ages, and experiences.



⁵¹ Exec. Order No. 01.01.2024.25 (2024). <u>https://mdod.maryland.gov/Documents/EO%2001.01.2024.25%20Maryland%20Plain%20</u> Language%20Initiative%20(1).pdf

⁵² Weir, E., Allison, C., & Baron-Cohen, S. (2021). The sexual health, orientation, and activity of autistic adolescents and adults. *Autism Research*, 14(11). https://doi.org/10.1002/aur.2604

APPENDICES

Appendix A: Governing Legislation

Maryland Human Services Code § 7-111 (2023)⁵³

(a) (1) There is a State Coordinator for Autism Strategy in the Governor's Office of Community Initiatives.

(2) The Governor shall appoint the State Coordinator for Autism Strategy.

(b) The State Coordinator for Autism Strategy, in consultation with the Advisory Stakeholder Group on Autism–Related Needs established under § 7–112 of this subtitle, shall:

- (1) identify and evaluate existing public, private, and nonprofit services for individuals with autism and their families;
- (2) on or before July 1, 2021, develop a strategic plan for addressing autism-related needs in the State, including, at a minimum, needs in the areas of employment, housing, health care, training for first responders and criminal justice professionals, and identification and intervention;
- (3) identify national benchmarks and other performance measures to be included in the strategic plan and used in evaluating the success of the State in addressing autism-related needs; and
- (4) monitor and evaluate the implementation of the strategic plan and the success of the State in addressing autism-related needs, including success in meeting national benchmarks.

(c) The strategic plan required under subsection (b) of this section shall specify performance measures, including any national benchmarks, for monitoring and evaluating success in addressing autism–related needs in the State including, at a minimum, the following:

- (1) reducing the unemployment and underemployment rates of people with autism;
- (2) improving postsecondary transition services and graduation rates;
- (3) increasing degree–granting college admission and participation and postsecondary vocational internships and apprenticeships leading to licensure;
- (4) increasing the availability of safe, affordable, and accessible housing;
- (5) identifying and reducing the negative physical and mental health outcomes of people with autism, including:
 - (i) identifying and improving caregiver and family support and respite services;
 - (ii) evaluating need and implementation strategies for the adult autism waiver;
 - (iii) reducing wait times for the Autism Waiver Registry;
 - (iv) promoting social inclusion and understanding for people with autism; and
 - (v) ensuring equitable access to diagnostic and therapeutic support services in rural areas and for underserved populations; and

⁵³ Human Services §7–111. (2023). Maryland.gov; Maryland General Assembly. <u>https://mgaleg.maryland.gov/mgawebsite/Laws/</u> <u>StatuteText?article=ghu§ion=7-111&enactments=false</u>



- (6) evaluating the need for and making recommendations regarding training programs for law enforcement, criminal justice professionals, or other first responders that address the effective recognition of and response to the needs of individuals with autism and their caregivers.
- (d) (1) On or before July 1 each year, beginning in 2021, the State Coordinator for Autism Strategy shall submit a report to the Secretary of Disabilities, the Governor, and, in accordance with § 2–1257 of the State Government Article, the General Assembly on the development, implementation, and effectiveness of the strategic plan required under subsection (b) of this section.
 - (2) Within 30 days after a report required under paragraph (1) of this subsection is submitted, the State Coordinator for Autism Strategy shall publish the report on the Department's website.
- (e) (1) For fiscal year 2023 and each fiscal year thereafter, the Governor shall include in the annual budget bill an appropriation to fund the position of State Coordinator for Autism Strategy and the Advisory Stakeholder Group on Autism–Related Needs.
 - (2) For fiscal year 2024 and each fiscal year thereafter, the Governor shall include in the annual budget bill an appropriation in an amount sufficient to fund one support staff position for the State Coordinator for Autism Strategy.

Maryland Human Services Code § 7-112 (2023)54

- (a) There is an Advisory Stakeholder Group on Autism-Related Needs.
- (b) The Advisory Stakeholder Group on Autism–Related Needs consists of the following members:
 - (1) one member of the Senate of Maryland, appointed by the President of the Senate;
 - (2) two members of the House of Delegates, appointed by the Speaker of the House;
 - (3) the State Superintendent of Schools, or the State Superintendent's designee;
 - (4) the Secretary of Disabilities, or the Secretary's designee;
 - (5) the Secretary of Human Services, or the Secretary's designee;
 - (6) the Secretary of Health, or the Secretary's designee;
 - (7) the State Coordinator for Autism Strategy;
 - (8) one representative of the Maryland Speech–Language–Hearing Association;
 - (9) one representative of the Maryland Developmental Disabilities Council;
 - (10) one representative of the Maryland Occupational Therapy Association;
 - (11) one representative of The ARC Maryland;
 - (12) one representative of Pathfinders for Autism;
 - (13) one representative of Itineris;
 - (14) the following members, appointed by the Governor:
 - (i) a school psychologist;
 - (ii)a physical therapist;

⁵⁴ Human Services §7–112. (2023). Maryland.gov; Maryland General Assembly. <u>https://mgaleg.maryland.gov/mgawebsite/Laws/</u> <u>StatuteText?article=ghu§ion=7-112&enactments=False&archived=False</u>



(iii) a pediatrician;

- (iv) two parents of children with autism;
- (v) two self-advocates with autism;
- (vi) one representative of public universities in the State;
- (vii) one representative of local public school systems in the State; and
- (viii) one representative from the business community; and
- (15) any additional members with expertise or experience in autism–related needs as considered necessary, appointed by the State Coordinator for Autism Strategy.

(c) The State Coordinator for Autism Strategy shall chair the Advisory Stakeholder Group on Autism–Related Needs.

(d) The Governor's Office of Community Initiatives shall provide staff for the Advisory Stakeholder Group on Autism–Related Needs.

(e) In appointing members under subsection (b) of this section, the appointing authority shall consider the geographical diversity of the State so that the composition of the Advisory Stakeholder Group on Autism–Related Needs reflects the various communities of the State.

- (f) A member of the Advisory Stakeholder Group on Autism-Related Needs:
 - (1) may not receive compensation as a member of the Advisory Stakeholder Group on Autism–Related Needs; but
 - (2) is entitled to reimbursement for expenses under the Standard State Travel Regulations, as provided in the State budget.

(g) The Advisory Stakeholder Group on Autism–Related Needs shall work with the State Coordinator for Autism Strategy to:

- (1) identify and evaluate existing services for individuals with autism and their families;
- (2) develop a strategic plan for addressing autism-related needs in the State;
- (3) promote, monitor, and evaluate implementation of the strategic plan; and
- (4) recommend and implement changes to the strategic plan.
- (h) (1) The Advisory Stakeholder Group on Autism–Related Needs shall hold its initial meeting on or before December 31, 2020.
 - (2) Beginning in 2021, the Advisory Stakeholder Group on Autism–Related Needs shall meet quarterly each calendar year.

Appendix B: ASGARN Members

Thank you to the ASGARN members who contributed to the creation of this strategic plan.

Adam Shafer Jones

Self-Advocate with Autism

Ami Taubenfeld

Parent of Autistic Daughter, Co-Founder & Executive Director, Itineris

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Devan Southerland, MSHSA Parent of Child with Autism & Founder, Brown on the Spectrum

Elizabeth Benevides Director of Outreach, Hussman Institute for Autism

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Fatima Salem, MS, C.C.C-SLP Speech Language Pathologist, Kennedy Krieger (CASSI)

Gregory Robinson, MPH Self-Advocate with Autism & Deputy Director of Public Policy, Autistic Self Advocacy Network (ASAN)

JaLynn Prince

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Janet Furman Director of Children's Services, Developmental Disabilities Administration

Jess L. Wilcox Cowing, Ph.D. Autistic Self-Advocate & Professor

Del. Julie Palakovich Carr House of Delegates, Maryland General Assembly

Anne Blackfield Deputy Secretary, Maryland Department of Disabilities

Lisa Wiederlight, M.P.P. Parent Advocate of Child with Autism & Founder, My Heart's Home

Ly Xinzhèn Zhǎngsūn Brown (Lydia X. Z. Brown), J.D. Autistic Self-Advocate & Director of Public Policy, National Disability Institute Lecturer, Georgetown University

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APPENDIX

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Rachel Leah Kraus, LCSW-C Self-Advocate with Autism & Parent of Autistic Child

Rachel London Executive Director, Developmental Disabilities Council

Raymond L Marshall President Emeritus, Arc of Maryland

Rebecca Rienzi Executive Director, Pathfinders of Autism

Roger Thibaudeau

Parent of Child with Autism & Engineer, Johns Hopkins Applied Physics Lab

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