Advisory Stakeholder Group on Autism-Related Needs

Meeting Agenda

March 12, 2024 1-2:30 PM

# ASGARN ATTENDEES

Adam Shafer Jones

Christy Russell

Devan Southerland, MS

Elizabeth Benevides

Emily Arker

Greg S. Robinson, MPH

JaLynn R. Prince

Janet Furman

Jess L. Wilcox Cowing, PhD

Lisa Belcastro

Lisa Wiederlight

Lydia X. Z. Brown, JD

Melissa Rosenberg, MA

Nancy Forsythe, EdS

Nicole LeBlanc

Nikki Stokes

Rachel Leah Kraus, LCSW-C

Rachel London

Ray Marshall

Rebecca Rienzi

Ryan Roddey

Victoria Rodríguez-Roldán

Yoreidy Vasquez-Tavarez, PhD, ABPP

# MEETING GUIDELINES

Victoria introduced Meeting Guidelines. Purpose 1 of the meeting is to create a safe, positive, and inclusive environment for the advisory group, participants, staff, and the public. Purpose 2 is to create a safe space for diversity of contributors, thoughts, and ideas. Additional meeting Guidelines included the following:

* Assume positive intent on the part of advisory members, moderators, participants, and staff.
* Listen actively. Allow others to complete their thoughts, listening to listen, and not listening to respond.
* One speaker at a time, prioritizing those who haven’t spoken yet.
* Default to “both/and” thinking instead of either/or thinking.
* Members of the public, please wait for the open forum section to speak.

# ROLL CALL

ASGARN members were asked to notify their presence as Ellis Sardorian read their names off the slide of ASGARN membership. An ASGARN [quorum](https://www.merriam-webster.com/dictionary/quorum) was in attendance.

# OPENING REMARKS – VICTORIA

Victoria Rodríguez-Roldán stated the goal of completing an Autism Strategic Plan before the end of the fiscal year on June 30, 2024. Since then, there have been many subcommittee meetings. They have produced many incredible ideas and recommendations. The sheer amount means that many will not be included. Victoria thanked the general assembly and membership in attendance.

# **PRESENTATION** (Highlights)

* ASGARN has hired Ellis Z Sardorian as an administrative coordinator.
* Survey completed to revise Mission & Vision statement.
  + MISSION: 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.
  + VISION: 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 live up to their highest potential and as independently as possible.
* Strategic Planning Timeline Review
  + January 2024: Subcommittees began their work with regular meetings to draft a report on their subject. Victoria has created a workbook to support ASGARN members in creating reports on their subject matters. These workbooks review theories of change, metrics of success, action plans and policy levers to create reports.
  + Mid April 2024: Subcommittees submit reports to the Coordinator of their recommendations and ideas for the strategic plan. These reports will be made available to the public. They will have been produced by experts in their field and those with lived experience. The Autism State Coordinator, Victoria Rodríguez-Roldán, will use these reports to produce the Maryland State Autism Strategic Plan.
  + Memorial Day 2024: Coordinator has a draft to provide to MDOD leadership and to ASGARN at a possible June meeting.
  + June 30 2024: The end of the fiscal year. Submission of the strategic plan to the state.
* The goal of the strategic plan is to help ensure the promotion of equality of opportunity, access, and choice for all autistic Marylanders.

# SUBCOMMITTEE UPDATES

## EDUCATION

* **Emily Arker:** Considered a wide range of needs of various ages, including transitions into higher education and employment.

## HOUSING & COMMUNITY INTEGRATION

* **Lisa Wiederlight:** Really enjoyed the work. Focusing on increasing access to affordable and accessible housing via community partnerships. They are considering various funding pathways and how local resources impact community integration. The workbook has supported their work in a variety of impactful considerations, such as environmental considerations for housing and community integration.

## SAFETY & TRAINING

* **Rebecca Rienzi:** The committee is examining existing training requirements and opportunities for law enforcement, mobile crisis, and first responders units statewide. The committee has taken a stance of “guardianship as a last resort, rather than the only resort” regarding the options presented to parents. They are also considering how to maintain the safety of those within guardianships, especially when guardianship changes.
* **Lisa Wiederlight:** Looking forward to upcoming conversations on abuse and neglect in home and provider-based situations, such as by direct support professionals.

## EMPLOYMENT/ TRANSPORTATION

* **Victoria Rodríguez-Roldán:** Considering the data available around unemployment vs. employment. Additionally, they are exploring hiring programs, know your rights materials, and training for employers and expanding diversity hiring programs. Transportation is very connected, such as cognitively accessible driver’s education available at driving schools, increased access to public transportation, and how to expand that into rural areas.

## HEALTH

* **Victoria Rodríguez-Roldán:** Committee has discussed topics such as diagnostic access and healthcare access.
* **Jess Wilcox-Cowing:** Discussed barriers to access, expanding modes of support beyond one model.
* **Jess Wilcox-Cowing:** Incentivizing medical care providers and medical school graduates to locate themselves in rural areas. Incentivizing autistic people to enter health professions of all kinds.

# NEXT STEPS

* ASGARN vacancies for a physical therapist and pediatrician. Interested parties can apply with the [Governor’s Office of Appointments](https://govappointments.maryland.gov/).
* Next quarterly meeting is scheduled for May 21, 2024. After that the Strategic Plan will be launched.

# OPEN DISCUSSION

## ASGARN Members

* **Emily Arker:** There used to be a pediatrician on ASGARN while it was hosted under the governor’s office. Could anyone track them down and ask them to reapply?
* **Victoria Rodríguez-Roldán:** If someone can identify them and ask them to reapply, that would be wonderful. Open to following up on leads to fill the vacancies offline.
* **JaLynn Prince:** What are the regulations in MD for continuing education of physicians and medical staff, and how can we influence medical schools in MD to learn more about autism?
  + **Rachel Leah Kraus**: Health Subcommittee has discussed this. It is most important to learn from professionals in the field who are also autistic in continuing education classes.
  + **Victoria Rodríguez-Roldán:** Also considering how to establish a pipeline to support the development of autistic healthcare professionals.
* **Victoria Rodríguez-Roldán:** Discussed often in the Health Subcommittee. They are revising the existing education process and considering appropriate policy levers.
* **Rachel Leah Kraus:** Has the Employment Committee discussed supporting autistic people in competitive employment through accommodations processes, navigating rights violations, and discrimination? Particularly in relation to advocacy.
  + **Ellis Sardorian:** The Office of Disability and Employment Policy has a [Jobs Accommodations Network](http://askjan.org) with a wide variety of needs and accommodations for the workplace. They also answer emails from the public.
  + **Victoria Rodríguez-Roldán:** I can see how that work may fall upon caseworkers and direct support professionals. It is worth exploring. Having subcommittees interact may help flesh out ideas where their work intersects, such as this one.
  + **Lisa Belcastro:** We’re looking at the [State As A Model Employer (SAME)](https://seed.csg.org/policy-curricula/state-as-a-model-employer/) Federal recommendations to Maryland.
* **Adam Shaffer Jones:** How does the state support mental health concerns such as depression?
  + **Victoria Rodríguez-Roldán:** A common barrier that has been identified by the committee is that when they co-occur with autism, autism is the only one that is identified and treated. This happens with both mental and physical health. That is why there is such a high need for education.
  + **Jess Cowing:** There is a barrier with many practitioners lacking a neurodiversity affirming approach. Many practitioners
  + **Greg Robinson:** Another barrier related to this is lack of provider competence and confidence in supporting individuals who also have intellectual and/or communication disabilities. The focus has been on making sure there are providers who can provide treatment and to enhance care.
* **JaLynn Prince:** There has been a recent movement in other states to inform judges about autism so that meltdowns are considered in sentencing.
  + **Victoria Rodríguez-Roldán:** I wouldn’t recommend a mandate, as the legal system governs itself.
  + **Rachel London:** That is already in the Council’s 5 year state plan. Working with Disability Rights MD and Developmental Disability Center of MD to develop information, resources, and training for judges and attorneys in both the criminal and larger court systems.
  + **Victoria Rodríguez-Roldán:** The committee has also discussed what happens when the autistic person is the defendant as opposed to the accused and presumption of innocence. There are many wonderful ideas, and again, I’m not sure what will make it into the Strategic Plan as there are so many good ones.

# CLOSING REMARKS/ADJOURNMENT – VICTORIA RODRÍGUEZ-ROLDÁN

Lydia X. Z. Brown motioned to adjourn. Rebecca Rienzi seconded. Meeting adjourned.