

# NEW JERSEY SELF-ADVOCACY PROJECT



## Accept the Unexpected:

Julia and Ray Speak Up About  
Autism Acceptance

STAY HEALTHY AT HOME WEBINAR SERIES

JUNE 7, 2022 FROM 2 - 3 PM

# INTRODUCTION

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- ▶ Ashley Ritchey, Director & Erin Smithers, Assistant Director of the [New Jersey Self-Advocacy Project \(NJSAP\)](#)
- ▶ NJSAP has been a Division-funded program of The Arc of New Jersey since 1983
- ▶ NJSAP supports the state's largest network of individual self-advocates and self-advocacy groups
- ▶ NJSAP provides comprehensive training and resources to self-advocates, Direct Support Professionals, and agency personnel

# INTRODUCTION

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- ▶ **Julia Simko** is a proud member of the autism community. She was a State Queen for the New Jersey Miss Amazing pageant in 2016 and 2019, graduated from New Jersey Partners in Policymaking in 2020, and is part of Council 3 of the New Jersey Statewide Self-Advocacy Network. Julia loves to read, watch movies, sing, do improvisation, and takes part in advocacy of all types whenever she can.
- ▶ **Ray Vercruysse** has been a member of Council 3 of the New Jersey Statewide Self-Advocacy Network since 2020. Ray participates in many groups for his many interests, like gaming, knitting, and socializing. Julia and Ray have one child, a son named Kip.

TYPE YOUR  
QUESTIONS,  
COMMENTS,  
FEEDBACK  
IN THE Q&A  
BOX

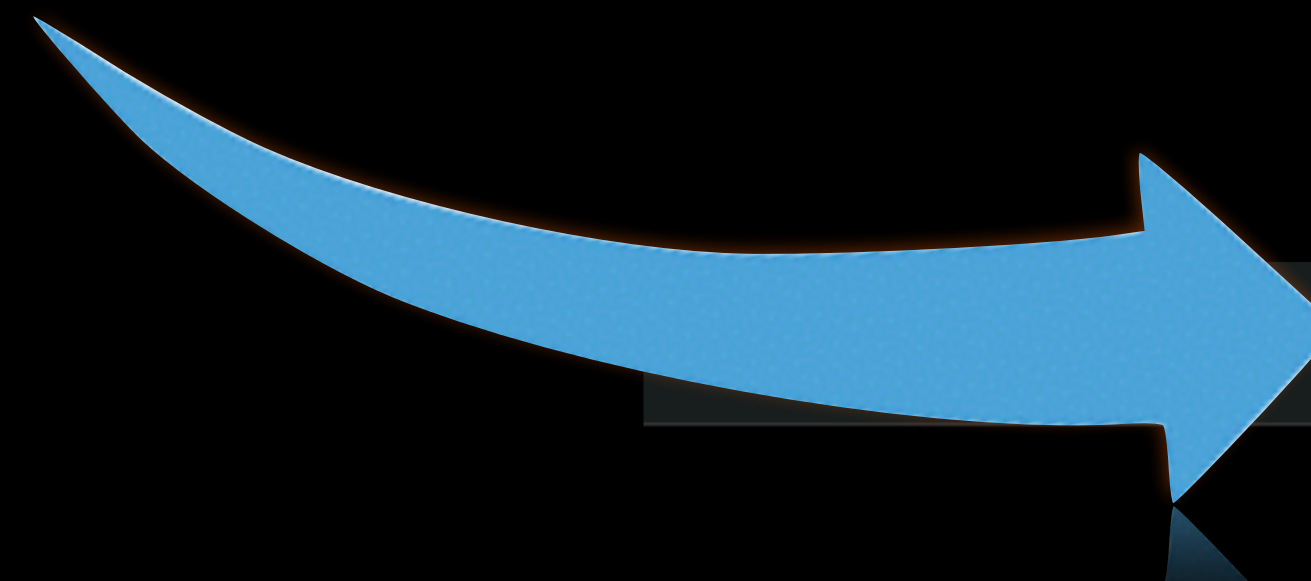
Q&A

**Welcome**  
Feel free to ask the host and  
panelists questions

Hello! I am a test question. How are you?

Send anonymously

Cancel Send



 Raise Hand

 Q&A

YOU CAN ENABLE CLOSED  
CAPTIONING BY CLICKING ON  
THE **LIVE TRANSCRIPT** BUTTON



# TODAY, WE WILL DISCUSS:

- Person First Language vs. Identity First Language
- Understanding Behaviors and Communication Through ASD
- Understanding Applied Behavior Analysis (ABA) and How It Is Perceived by the ASD Community



THE VIDEOS IN  
THIS WEBINAR ARE  
THE THOUGHTS,  
FEELINGS AND  
LIVED EXPERIENCES  
OF JULIA AND RAY.

PERSON FIRST  
LANGUAGE AND  
IDENTITY FIRST  
LANGUAGE ARE  
BOTH USED  
IN THIS WEBINAR





# WHAT IS STIMMING?



“The repetitive performance of certain physical movements or vocalizations.”

# WHY DO PEOPLE STIM?



- Enjoyment
- An attempt to gain sensory input
- An attempt to reduce sensory input
- To deal with stress and anxiety
- A form of communication

PERSON FIRST

VS.

IDENTITY FIRST

# WHAT IS PERSON FIRST LANGUAGE?



“Puts the person before the disability”

# WHAT IS IDENTITY FIRST LANGUAGE?

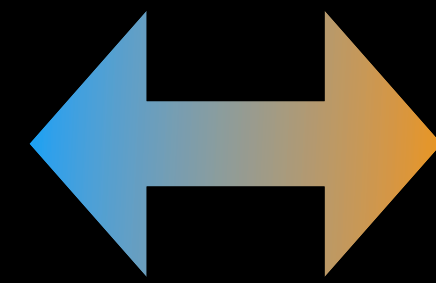
“Stating a descriptor of a person first”



# PERSON FIRST

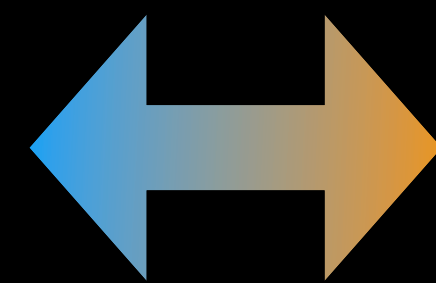
# IDENTITY FIRST

- Person With a Disability



- Disabled Person

- Person with Autism Spectrum Disorder



- Autistic Person



“Which language  
do you prefer to  
use/hear?”







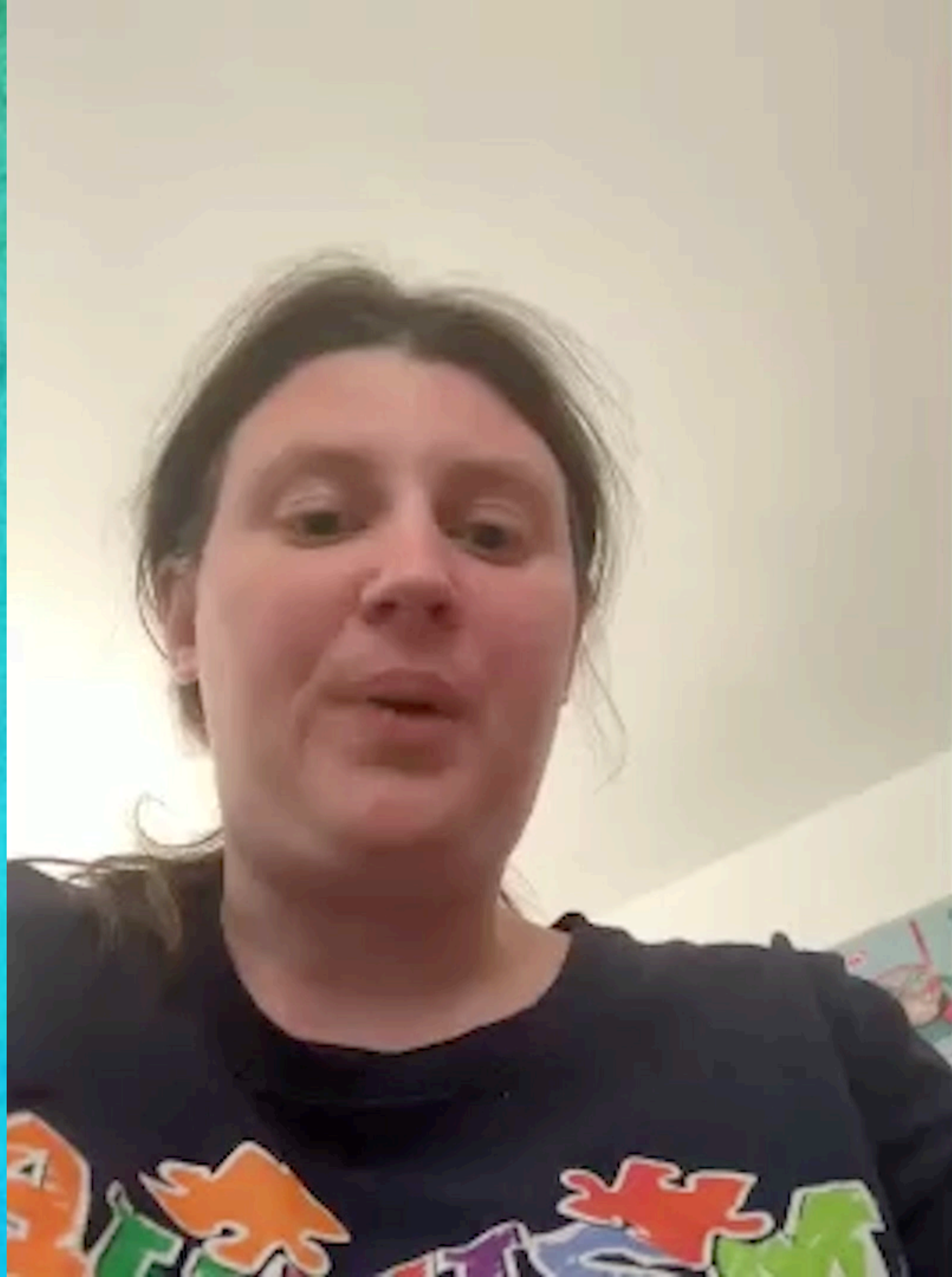
**The LGBTQA+ community sets a great precedent to let people know your personal pronouns. Could we also do this with preferred language?**

POSITIVE  
INTERACTIONS  
WITH PEOPLE WITH  
ASD

"How do you  
want to be  
treated?"













APPLIED BEHAVIOR  
ANALYSIS THERAPY  
(ABA)  
AND STIMMING

# WHAT IS ABA?

“The practice of applying the psychological principles of learning theory in a systematic way to modify behavior.”





“How is *stimming*  
related to  
communication?”

“How is ABA  
perceived in your  
community?”















# SCERTS MODEL

<https://scerts.com>

# Goals of SCERTS for Children With Autism

Generalized skills



Functional academic skills



Social and play skills



Functional & spontaneous communication



Positive approaches toward behavior problems



EMPATHY

AND

ASD



“What are some stereotypes regarding empathy and people with ASD?”







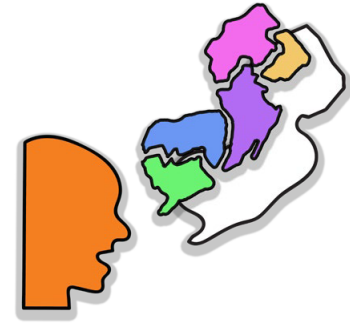


LEGISLATIVE  
ADVOCACY



“How do you  
feel about policy  
advocacy?”





# New Jersey Self-Advocacy Project & Statewide Self-Advocacy Network

A program of The Arc of New Jersey since 1983

December 7, 2021

Good morning members of the Department of Human Services and thank you for the opportunity to provide input into the 2022-2023 budget.

My name is Julia Simko and I live in Mercer County. I am a graduate of the Partners in Policymaking Program. I am a member of Council 3 with the New Jersey Statewide Self-Advocacy Network (NJSSAN). I was also a two time State Queen of the Miss Amazing Pageant. I have presented on panels with The Boggs Center and I am an advocate for people with Intellectual and Developmental Disabilities (IDD) all over New Jersey. My journey with self-advocacy has been so empowering. I am continuously learning how to speak up for myself and for others around me.

I also recently became a new parent in August 2021. My experience with the government programs designed to help support me as a new mother were very unaccommodating. I felt the staff and programs were designed to separate our family instead of offering training and support to keep us together. As a family, we felt like we were set up to fail. The parents' interests, physical health, and mental health were not considered in this process; it was a very traumatic experience. We felt ignored and dismissed. They seem to have made assumptions over what they know from their experiences without getting to know us independently.

I am coming to you today to ask you for more support for families who have parents with IDD. There should be trainings and programs offered for new parents and family members. Government programs should be designed to keep families together and offer the supports that are needed to make sure every member of the family is thriving. There should be classes that people with IDD can attend that help support the family structure, teach, and prepare the future parents about the process of evaluations and programs that will become involved in the life of their new child. A new parent should not be blindsided by the tests, evaluations, events, and the processes of how the programs operate. There should be accommodations given to those who need it; we did not receive



Supporting the rights of people with intellectual and developmental disabilities  
985 Livingston Avenue, North Brunswick, NJ 08902  
Phone: 732-743-8345 Fax: (732) 749-8514  
E-mail: [NJSAP@arcnj.org](mailto:NJSAP@arcnj.org)  
[www.njselfadvocacyproject.org](http://www.njselfadvocacyproject.org)



# New Jersey Self-Advocacy Project & Statewide Self-Advocacy Network

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December 7, 2021

Good morning members of the Department of Human Services and thank you for the opportunity to provide input into the 2022-2023 budget. I really appreciate the chance to share my testimony with you today.

My name is Ray Verduyze and I live in Mercer County. I just started getting more involved in self-advocacy and really appreciate the opportunity to learn how to speak up for myself. I am always looking for new ways to become as independent as I possibly can. My parents have taken care of me for my whole life but I was taught very little about how to live independently and how to get services to live on my own. Unfortunately, I know that this is a common situation for a lot of people with Intellectual and Developmental Disabilities (IDD).

I also recently became a new parent in August 2021. My experience with the government programs designed to help support me as a new father were very complicated and hard to navigate. I was very frustrated to learn that there are very little resources out there to help people with IDD maneuver through adulthood on their own.

I am coming to you today to ask you for more support for people with IDD to learn life skills, in a hands-on environment. There should be classes that teach people with IDD life skills, like how to do their taxes, how to rent or buy a house or apartment, how to navigate housing vouchers, how to buy a car, cook recipes, practice upkeep of their home, learn basic home economic skills, how to balance a bank account and manage a credit card, enroll in school, sign up for insurance benefits and other state programs like Medicaid and Medicare, how to traverse any other programs that are available for people with IDD, and learn any other skills that would help people lead a more independent life.

It would benefit so many people if there were resources allocated in the 2022-2023 budget that can give the opportunity for people with IDD to practice these skills in their actual lives, and not just be given paper resources. These classes should be accessible for people with all abilities and affordable for every lifestyle. It



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[www.njselfadvocacyproject.org](http://www.njselfadvocacyproject.org)

*Assembly Budget Committee (Budget Hearings Only)*

*Monday, March 21, 2022 - 12:30:00 PM*



Play (k)



0:01 / 2:57





## DD Awareness Month: Advocacy Tutorials

8 videos • 34 views • Last updated on Mar 30, 2022

Public



No description



New Jersey Self-Advocacy Project (NJSAP)

SORT



### NJ Voter Registration

New Jersey Self-Advocacy Project (NJSAP)



### How to Develop Testimony

New Jersey Self-Advocacy Project (NJSAP)



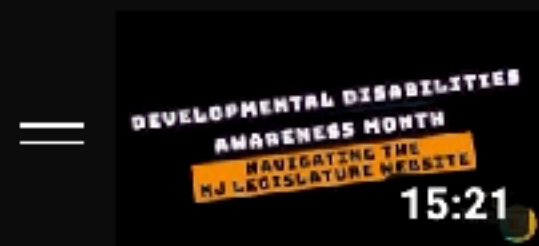
### Technology Survey and Tutorials

New Jersey Self-Advocacy Project (NJSAP)



### Action Alerts

New Jersey Self-Advocacy Project (NJSAP)



### Navigating the NJ Legislature Website

New Jersey Self-Advocacy Project (NJSAP)



### Find your Legislators

New Jersey Self-Advocacy Project (NJSAP)



### Action Alerts

New Jersey Self-Advocacy Project (NJSAP)

FINAL THOUGHTS

“What can be done  
to improve the  
quality of life for  
people with ASD?”









# **TAKE AWAYS**

- **Talk To The Person Directly**
- **Use Respectful Language**
- **Be Patient and Understanding**
- **Don't Assume a Lack Of Knowledge**
- **Behavior is Communication**
- **Everyone is Different**

NEW JERSEY  
SELF-ADVOCACY  
PROJECT

# FREE VIRTUAL TRAININGS



The New Jersey Self-Advocacy Project has partnered with The Horizon Foundation for New Jersey to help you learn more about health, wellness, and being the best you! We are happy to tailor our presentation(s) to suit the needs of your group. Contact us to set up a time and date at your location! The New Jersey Self-Advocacy Project Team will provide free workshops on the following topics:



## Connect With Us!

Phone & Fax: (732) 749-8514

Email: [NJSAP@ArcNJ.com](mailto:NJSAP@ArcNJ.com)

[www.Facebook.com/NewJerseySAP](http://www.Facebook.com/NewJerseySAP)









[www.Twitter.com/NJSAP](http://www.Twitter.com/NJSAP)

[www.NJSelfAdvocacyProject.org](http://www.NJSelfAdvocacyProject.org)



Foundation for New Jersey

# MY WEEK WITH NEW JERSEY SELF-ADVOCACY PROJECT

MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY
<ul style="list-style-type: none"> <li>•Check social media feed for Veronica's new nutrition video</li> </ul>  	<ul style="list-style-type: none"> <li>•Watch the new Stay Healthy at Home webinar at 2pm</li> </ul> 	<ul style="list-style-type: none"> <li>•Interactive Zoom event for HLP:Live at 11am</li> </ul>  <ul style="list-style-type: none"> <li>•Check social media feed for IHT's new workout video</li> </ul> 	<ul style="list-style-type: none"> <li>•Play this week's Brain Game on Zoom at 1pm</li> </ul> 	<ul style="list-style-type: none"> <li>•Check social media feed for Erin's new recipe video</li> </ul>  <ul style="list-style-type: none"> <li>•HLP:Live! It's Fitness Friday with IHT on Zoom at 1pm</li> </ul> 
<p><b>TO DO LIST:</b></p> <ul style="list-style-type: none"> <li>•Sign up for NJSAP's email list</li> <li>•Request a virtual group training</li> <li>•Make a social media post using this month's hashtag</li> </ul>		<ul style="list-style-type: none"> <li>•Participate in an advocacy campaign or Action Alert</li> </ul>	<p><b>REMINDERS + NOTES:</b></p> <ul style="list-style-type: none"> <li>•Mark my calendar with all upcoming activities</li> <li>•Reminder: Each NJSSAN Council meets every month</li> <li>•Remember: Self-Advocacy means to SPEAK UP!</li> </ul>	



Find out more at [www.njselfadvocacyproject.org](http://www.njselfadvocacyproject.org)

Facebook: @NewJerseySAP / Instagram: @NewJerseySAP / Twitter: @NJSAP

# EVERYTHING IS AVAILABLE ON:



[www.arcnj.org/programs/njsap/videos.html](http://www.arcnj.org/programs/njsap/videos.html)



<https://www.instagram.com/newjerseysap/>



<https://www.facebook.com/NewJerseySAP/>



<http://www.twitter.com/njsap>



[Click Here To Sign Up!](#)



# Healthy Lifestyles Project

**LIVE**



Live Healthy,  
Together







# Resources

- ▶ NJSAP: <http://www.arcnj.org/programs/njsap/>
- ▶ NJSAP Webinars: <https://www.arcnj.org/programs/njsap/webinars.html>
- ▶ NJSAP Youtube: [www.arcnj.org/programs/njsap/videos.html](http://www.arcnj.org/programs/njsap/videos.html)
- ▶ NJSAP HLP: [www.HealthyLifestylesProject.org](http://www.HealthyLifestylesProject.org)
- ▶ Healthy Lifestyles Project Live!: <https://www.arcnj.org/information/healthy-lifestyles-project/hlplive.html>
- ▶ NJSAP Email List Registration: [https://visitor.r20.constantcontact.com/manage/optin?v=001PkT5eHO4C2JrwfPw-p5rdqMeT2hyB3H\\_I\\_8-6Pyz\\_LIEdaG9FrebFmRUe0vIVTdajyOgbl3eJPfej5\\_IYANtZZVdceO7DjpChlHrmndLyH8%3D](https://visitor.r20.constantcontact.com/manage/optin?v=001PkT5eHO4C2JrwfPw-p5rdqMeT2hyB3H_I_8-6Pyz_LIEdaG9FrebFmRUe0vIVTdajyOgbl3eJPfej5_IYANtZZVdceO7DjpChlHrmndLyH8%3D)
- ▶ Positive Pulse Sign Up Link: [https://visitor.r20.constantcontact.com/manage/optin?v=001PkT5eHO4C2JrwfPw-p5rdhN0hs6zmFCpw\\_-qljyChHCjo8caQS7OnfriaJZQWdRzRL\\_w8oJ-UatsYCC7QBeHthjpotosACKEiDlw07cbjhkra9kPcBx4gW6FI9bf\\_XOk0QqcieR1PU3-NjnEHKe3A2eQ4R1h09jV7UMSM9iFawgMIB9xGmVFCg==](https://visitor.r20.constantcontact.com/manage/optin?v=001PkT5eHO4C2JrwfPw-p5rdhN0hs6zmFCpw_-qljyChHCjo8caQS7OnfriaJZQWdRzRL_w8oJ-UatsYCC7QBeHthjpotosACKEiDlw07cbjhkra9kPcBx4gW6FI9bf_XOk0QqcieR1PU3-NjnEHKe3A2eQ4R1h09jV7UMSM9iFawgMIB9xGmVFCg==)
- ▶ NJSAP Twitter: <http://www.twitter.com/njsap>
- ▶ NJSAP Instagram: <https://www.instagram.com/newjerseysap/>
- ▶ NJSAP Facebook: <https://www.facebook.com/NewJerseySAP/>
- ▶ NJSAP HLP LIVE Sign Up Link: [https://visitor.r20.constantcontact.com/manage/optin?v=001PkT5eHO4C2JrwfPw-p5rdqMeT2hyB3H\\_I\\_8-6Pyz\\_LIEdaG9FrebFmRUe0vIVTdajyOgbl3eJPfej5\\_IYANtZZVdceO7DjpChlHrmndLyH8=](https://visitor.r20.constantcontact.com/manage/optin?v=001PkT5eHO4C2JrwfPw-p5rdqMeT2hyB3H_I_8-6Pyz_LIEdaG9FrebFmRUe0vIVTdajyOgbl3eJPfej5_IYANtZZVdceO7DjpChlHrmndLyH8=)
- ▶ Identity First Language: <https://ausometraining.com/identity-first-language/>
- ▶ ABA Therapy: <https://www.appliedbehavioranalysisedu.org/what-is-aba/>
- ▶ SCERTS Diagram: <https://www.verywellhealth.com/scerts-model-autism-4173802>
- ▶ SCERTS Website: <https://scerts.com/the-scerts-model/>

# QUESTIONS?

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- ▶ Stay in touch: [ARitchey@ArcNJ.org](mailto:ARitchey@ArcNJ.org)
- ▶ Stay in touch: [ESmithers@ArcNJ.org](mailto:ESmithers@ArcNJ.org)
- ▶  Phone & Fax: 732-246-2525 x22
- ▶  [twitter.com/NJSAP](https://twitter.com/NJSAP) or @NJSAP
- ▶  Facebook: [https://www.facebook.com/  
NewJerseySAP/](https://www.facebook.com/NewJerseySAP/)
- ▶  Instagram: [https://www.instagram.com/  
NewJerseySAP](https://www.instagram.com/NewJerseySAP)
- ▶ NJSAP Website: <http://www.njselfadvocacyproject.org>