



## **“Finding One’s Advocacy Community: Stories and Insights from the Disability Community”**

**Summary of a webinar from June 20, 2024**

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### **Introduction**

This webinar is about the Grassroots Project. Jennifer shared that the Grassroots Project’s goal is to help disability advocates at national, state, and local levels. The project connects advocates to each other. In this webinar, advocates share how they:

1. Stay informed
2. Work together
3. Take action to improve their communities and services

### **Panel of Disability Advocates**

**Panelists first talk about what is going well in their advocacy work.**

Allilsa advocates for mental health justice. He said that educating the community and providing resources is going well. They shared that many people in the disability community do not know that mental health disabilities are covered by disability laws. Allilsa thus finds that education and resources are helpful for the community.

Lola takes part in multiple types of advocacy. She is the Advocacy Coordinator on the Kansas Council on Developmental Disabilities. Lola has advocated to get rid of sheltered workshops in Kansas. She was part of a play about autism called *Rubik*. The play featured self-advocates. Lola said, “it is important to have accurate representation everywhere.”

**Next, panelists shared where they find their energy and capacity.**

Cody said his energy and capacity comes from his lived experience. His push for justice keeps him going. Cody also said that advocacy is tiring. Cody’s advocacy is part of his life. So, it is a natural focus of his.

Santa said that her energy comes from “wanting to make society better for people with disabilities.” She talked about how this takes time. It also takes different types of people to make change. She said that all people need to be present and have their voices heard. Santa hopes to encourage new advocates to keep fighting for equality.

**Last, panelists described how they connect across disability advocacy groups.**

Eric shared that all disability communities need to support each other. He said that some advocates will have the chance to speak up and make changes. Eric said that when you have a voice, you should use it to speak up for people who do not yet have a voice. Eric finished with, “it’s our responsibility as advocates to advocate for everyone.”



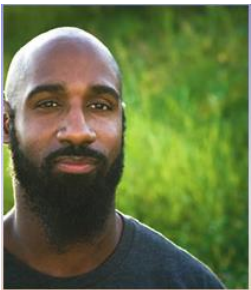
The speakers on this webinar were:



**Allilsa Fernandez** is a mental health and disability advocate, activist and consultant. They have worked with companies such as Facebook, Lionsgate, Verizon, and ReelAbilities Los Angeles. In addition, they have volunteered with Sylvia Rivera Law Project on shelter organizing, with Met Council on housing justice, and NYC mutual aid providing aid to people across NYC. Allilsa has also worked with diverse organizations, companies, and politicians such as Janos Marton, to create intersectional mental health policies. She graduated Magna Cum Laude from Stony Brook University with a bachelor's in psychology and completed her fellowships with The Coelho Center for Disability Law, Policy and Innovation, and Latino Justice Law Bound. Their work has been featured in Forbes Magazine and the Laura Flanders show.



**Cody Drinkwater** is the [Regional Self Advocacy Specialist for the Eastern Shore](#). He has a bachelor's degree from Towson University in history with a minor in English. He previously worked for the Wicomico County Public School System. In addition to his role at the DDA, he works as the Policy Coordinator for People on the Go of Maryland. He is on the Autism Spectrum and has executive functioning disabilities along with mild Cerebral Palsy. This makes the work he does for self-advocacy even more important. His job duties entail assisting individuals in the self-advocacy process, networking with providers, providing outreach and guidance to Self-Advocacy groups, and creating necessary trainings in the region. The main thing he likes about his work is helping and empowering people. He wants stakeholders to know they can always reach out to him. He's happy to help them.



**Eric Washington** is a former football player for the University of Minnesota and the University of Kansas. His football career ended on September 30th, 2006, due to a concussion and spinal cord injury. After recovering from the neck injury, he returned to graduate with a bachelor's degree in applied Behavioral Sciences. Today, Eric's life mission is to advocate for people like him – people with TBI, especially those who are also unhoused. He also serves as a strong advocate in the high school athletic community helping student athletes make educated decisions when taking a scholarship and helping their families understand the importance of not rushing back after injury. Eric was a faculty member for the NCAPPS Brain Injury Learning Collaborative. He is co-lead and member of the TBI TARC TAL-Group.



**Dr. Jennifer Johnson** is the Deputy Commissioner of the Administration on Disabilities (AoD), part of the U.S. Department of Health and Human Services' Administration for Community Living. AoD's mission is to equip individuals with disabilities of all ages with opportunities, tools, and supports to lead lives of their choice in their community. Its programs are working to create change and improve the lives of the estimated 61 million individuals with disabilities living in the US by advancing opportunities for inclusion and participation in the community, employment and financial well-being, and independence and self-determination. Dr. Johnson has served as the Deputy Commissioner since September 2019, with



a focus on improving the quality, accountability, and evidence base of AoD's programs and initiatives. She supports planning and oversight of AoD's \$355 million budget that funds a number of disability programs and projects across the US and its territories. Her 30-year career in government, academia, national organizations, and local school systems demonstrates a clear commitment to improving opportunities for people with disabilities to lead full lives in the community, with emphases on diversity, inclusion, and advancing a diverse array of programs for underserved and unserved individuals and communities.



**Lola Kernell** is a senior at Bishop Miege High School, where she is involved in Theatre, French Club, National Honor Society, and Campus Ministry. She has been on the Honor Roll each semester, received awards for French, Theology, and the Eric Druten Memorial Junior Scholarship. She is an active lector and server at Curé of Ars Catholic Church, is currently working on her highest-level award for American Heritage Girls and is involved in Down Syndrome Innovations ACE program. Lola works part time for the Royals and the Chiefs and has worked for Nautical Manufacturing and Fulfillment. Lola is a peacemaker, is friendly and outgoing, loves public speaking and being an advocate for others, and has great

technical computer skills. She is living her dream by working as an intern for Kansas Council on Developmental Disabilities



**Santa Perez** has been an Advocate for People with developmental disabilities and intellectual disabilities DD/IDD for most of her life. Her ultimate goal is to promote inclusion for all people no matter who they are. All people need to be included to have a democratic society. Santa is a founding member of People First of Nevada and active President Emeritus of the People First of Nevada. She believes that people with developmental and intellectual disabilities need to become Active Advocates in every aspect of their lives. They need to make their mark on the world. Along with People First of Nevada, Santa was instrumental in getting past three laws: The People First Respectful Language Law, The Signature Stamp Law, and

the Supportive Decision-Making, Law. Santa is a former member of the Nevada Governor's Council on Developmental Disabilities and sits on many State and National committees. She was appointed to The President's Committee for People with intellectual disabilities. She is the Chair of the sub-committee of Community Living and co-teachers at Virginia Commonwealth University in Disability, Diversity & Human Rights. Santa is a published author and blogger and the author of *Sitting At Eye Level: My Life as an Advocate, a Professional, a Woman, a Mom, and a Person with a Significant Disability*. Santa has earned a Bachelor of Arts degree in Psychology from Cal State Northridge.

### **Grassroots Project & Contact Information:**

*The Grassroots Project is an initiative from the Administration for Community Living to develop structures, processes, and relationships necessary to build the next generation of cross-disability, cross-generational, and culturally diverse leaders within the advocacy movement. It's aim is to connect, grow, and strengthen networks of grassroots advocacy and action coalitions supporting each other with the skills and knowledge to advocate for improvements in the quality of community-living supports. Grassroots Project webinars are open to the public, and are geared toward grassroots disability advocates, people with lived experienced of disability, human services administrators, and providers. All Grassroots Project webinars are recorded and currently archived at <https://www.hsri.org/project/the-grassroots-project>. Contact us at [grassroots@hsri.org](mailto:grassroots@hsri.org).*