GRASSROOTS PROJECT
ENGAGE CONNECT ADVOCATE

"Tools & Tips for Commenting on 1915(c) Waivers"

Summary of webinar: May 14, 2025

Background

The Grassroots Project started in 2023. We are now in our first full year at this scale. Our aim is to support national, state, and local disability coalitions and advocates in building networks to allow them to stay informed about policies that affect people with disabilities.

Introduction

This webinar is focused on tools and tips for commenting on 1915(c) waivers. Our speakers are:

1. Laura Bernas
2. Kate Brady
3. Jennifer Kucera
4. Susan Koller
5. Elizabeth Edwards

Kate Brady
Kate shared that the Grassroots Project works with many cross-disability coalitions. The project works at both the national and state level. The project also works with a State Agency partnership group.

Jennifer Kucera
Jennifer shared she currently chairs the Ohio Olmstead Task Force. The taskforce was formed in 2002. The task force's goal is to get the Medicaid agency to take them seriously. Their mission is to build a strong structure to support relationship building with coalitions. Their mission is to educate and advocate. They believe that change is a two-way street. Ohio was not doing anything to move folks out of institutions. Anyone outside of the institutions was trying to help get friends out. They were trying to move folks to the community. The national organization ADAPT helped them do sit-ins at federal offices.

The taskforce is not connected to any government agency. However, they are 501c3 nonprofit. This means they can only do little "a" advocacy. Little "a" advocacy is at the heart of what they do. They do not lobby. The group's work is mostly statewide. The taskforce lives the social and independent living model of disability. Jennifer also shared that Ohio has 3 waivers under 3 departments: Department of Medicaid, Department of Aging, and Department of Developmental Disabilities. Ohio uses a fee for service model.

The Aging Waiver is called PASSPORT waiver. In the Department of Disabilities, the waiver is called the DD Waiver.

Susan Koller
Susan shared that she wanted nothing to do with disability advocacy. Given her disability, it took over enough of her life. "She was happy just doing PR work." Due to her high support needs, she was not sure she could live on her own. She got a Home-Care waiver in grad school. Susan talked about how, in that first meeting about the waiver, you can get so overwhelmed. They give you so much info you don't have time to go into; you're just living your life. Susan did not really use a lot of services she needed due to her mother's natural support. Susan shared how she worried "Oh shoot my mother is my only caretaker. What happens if she falls or something?" Over the years she has heard many horror stories.

She eventually decided to go into a long-term care center. She chose a nursing home due to needing a lot more care, even though she is independent and likes to do things on her own. Nursing homes have lots of shortages and it was not good. She signed up for an advocacy class through AUCD. She moved onto a different, better waiver program faster by living in the nursing facility first. AUCD is how she got connected to Grassroots Project. Susan shared that in advocacy it would be easier to give feedback if stuff was accessible, publishing just the amendment to a waiver is ideal, and a glossary of terms to make it easier would also be helpful.

Elizabeth Edwards
Elizabeth shared that CMS has all approved waivers on the Medicaid website. Case managers may not know the waiver as much as you like. By reading the waiver you may find you are not being told what is out there. States must offer services to everyone on a waiver. A waiver is supposed to be a useful alternative to institutional living. This means it really should cover everything you need to live in the community, and not just exist. States have cut back waiver programs to point where disabled people are just surviving. Disabled people are the only ones who can tell the state what they need to exist.

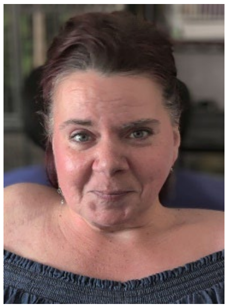
Speaker Bios

Laura Bernas is the Project Manager of the Grassroots Project whose work is driven by a passion for creating systems in which all people have access to liberation. Laura is particularly skilled at working with public agency staff to connect, grow, and strengthen advocacy and action coalition networks through a humanistic and person-centered lens. Laura is also highly skilled in strategic visioning and planning, creative communications and engagement, connecting disparate people and ideas, arts nonprofit creation, and organizational management. Laura is disabled with lived experience of mTBI and chronic illness.

Kate Brady PhD, ABD, is Co-Director of the Grassroots Project and project manager for other technical assistance and evaluation projects. She particularly appreciates opportunities to advance community response to critical public systems changes that align services with HSRI's goal to see all people living healthy, fulfilling lives as powerful, respected members of society.

Elizabeth Edwards is a Senior Attorney with the National Health Law Program where she advocates using education, policy, and litigation to ensure access to Medicaid and other services. Her work includes home and community-based services, eligibility and enrollment, non-discrimination, due process, managed care, and the fair use of automated decision-making systems including artificial intelligence.

Susan Koller lives in Cincinnati, Ohio. She has degrees in Mass Communication and in Public Administration, both from Wright State University. Before becoming a disability advocate in 2018, she worked in public relations for over 10 years. Susan enrolled in the University of Cincinnati Center for Excellence for Developmental Disabilities' (UCCEDD) Leadership Education in Neurodevelopmental and related Disabilities (LEND) Training Program as a Self-Advocate Trainee. Susan served on Disability Rights Ohio's Board. She serves on the UCCEDD's Community Advisory Committee. Susan is involved in other advocacy efforts with various organizations.



Jennifer Kucera was born with Spinal Muscular Atrophy and has been a self-advocate her entire life. She was a college math instructor but now she has dedicated her life to systems advocacy. She currently works at the Center for Disability Empowerment, in Columbus, Ohio, as their Healthcare Outreach Coordinator, chairs Ohio's DD Council, is on United Healthcare's National Advisory Board, and is the chair of the Ohio Olmstead Task Force.

Grassroots Project Information & Contact

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. Its 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 experience 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

Webinar recordings are also posted on YouTube:
https://www.youtube.com/@TheGrassrootsProject-hsri

Contact us at: grassroots@hsri.org