



**“It’s up to us, what kind of life we want to live:”
Promoting Meaningful Person-Centered Practices in Home and
Community-Based Service Delivery**

Summary of a webinar from September 22, 2022

Introduction

This webinar is about why people want to have choice and control over services they use. Many people use home and community-based services. They want to have control over the services they use. Here are some things home and community-based services help people with:

1. Employment
2. Transportation
3. Home care/ home health (like medications, housekeeping, and in-home therapy)
4. Activities of daily living (like bathing, dressing toileting and cooking)
5. Money management
6. Assistive Technology
7. Home Modifications

Most people who use these services say it helps them have a good life.

Personal Stories

Panelists shared their personal stories.

Person-centered services didn’t work for Bathey in the beginning. She didn’t have a voice for herself. It was difficult to have the life she wanted. Now she can make choices that she wants. People will help her, but she will make the choices on her own.

Héctor remembers living in a state hospital developmental center. When he lived there all his choices and decisions were made by other people. To Héctor, person-centered means “everything about me, with me.”

Reveca has a spinal cord injury. She has received services since she was a teenager. Reveca says, “There’s fear in speaking up about these things because maybe I might lose my services, and it shouldn’t be that way.” Reveca thinks we should feel safe talking about what we want.



NCAPPS

National Center on Advancing Person-Centered Practices and Systems

The speakers on this webinar were:



Lindsay DuBois is the project manager for the Rehabilitation and Research Training Center on Home and Community-Based Services Outcomes Research and Measurement. Dr. DuBois has more than 10 years of experience in disability research, with an emphasis on monitoring and evaluation of health inequities for people with disabilities. She is also passionate about knowledge translation and ensuring that research is accessible to and actionable for a variety of stakeholders.



Tonie Sadler is a post-doctoral fellow in Health Services and Outcomes Research at Northwestern University and the Center for Rehabilitation Outcomes Research at Shirley Ryan AbilityLab. Her research focuses on disability health services and policies that affect people with disabilities and their families throughout the life course. She has over ten years of research and practice experience with marginalized populations, specifically populations with disabilities and complex healthcare needs.



Bathey Fong is a 37-year-old self-advocate living in Hawaii. Bathey was born in American Samoa and is a person with a disability. She has two disabilities: a learning disability and cerebral palsy. Bathey is a college student and is also active in the community. She is president of the self-advocacy program for the Developmental Disabilities Council. She also works on emergency preparedness for people with disabilities. She has worked on a book with her team on teaching people with disabilities and their families how to run meetings and speak up for themselves.



Héctor Manuel Ramírez (them/they) is an Apache & Mexican Two Spirits person occupying space in Yaanga, Tongva (Los Angeles, California) the unceded ancestral lands of the Tongva/Kizh/Tatavin, Chumash & Fernandño Tataviám Band of Mission Indians. Héctor is an Autistic person who is hard of hearing & has a psychiatric disability. Hector does local, state, & federal level policy work in the areas of equity & disparities. Héctor is on the board of directors with Disability Rights California & the National Disability Rights Network where Héctor provides oversight & accountability.



Reveca Torres is an artist, filmmaker and disability advocate. She was paralyzed in a car accident as a teenager. Reveca started a nonprofit called BACKBONES after realizing that years of interaction and friendship with others living with spinal injuries (SCI) made a significant impact in her own life. Reveca wanted to ensure that others, especially those newly injured, had access to resources, information, and the same type of support she has had. Reveca is also co-director of ReelAbilities Film Festival Chicago and has curated touring photography and art exhibitions that showcase work of people with disabilities and bring awareness to disability rights.