

“My Choice, My Way:” Implementing Meaningful Person-Centered Practices

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Postdoctoral Fellow

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Background



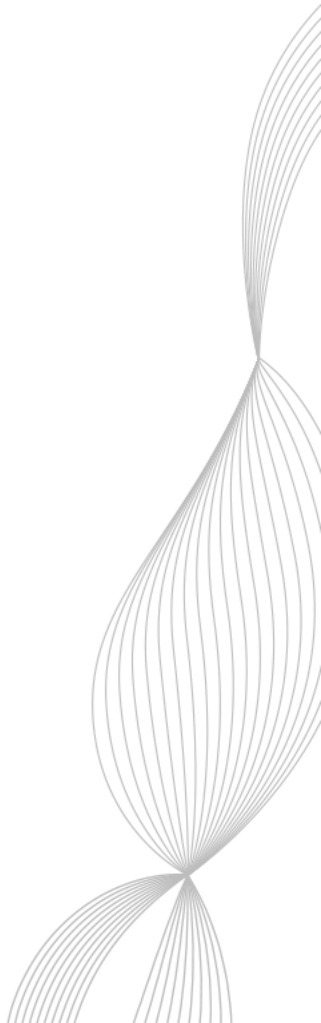
- Center for Rehabilitation Outcomes Research at Shirley Ryan AbilityLab receives five year grant (September 1, 2020 – August 31, 2025)
- Funded by the National Institute on Disability, Independent Living and Rehabilitation Research (US Department of Health and Human Services)
- NIDILRR Project Officer: Amanda Reichard



The Team



- John Abbate, MSW
- Lindsay DuBois, PhD
- Linda Ehrlich-Jones, PhD
- Allen Heinemann, PhD
- Sara Karon, PhD, RTI International
- Steve Lutzky, PhD, HCBS Strategies
- Bridgette Schram, PhD
- Niveda Tennety



Héctor Manuel Ramírez

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 them Tongva/Kizh/Tatavin, Chumash & Fernandeano Tataviam 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 in Disability, Native American, Latinx, Indigenous, LGBTQIA2S+, Immigrant, Undocumented Americans, & most impacted & highly marginalized communities during the COVID-19 pandemic. Hector is a member of Governor Newsom Behavioral Task Force and a commissioner with the California Commission on Disability Access.

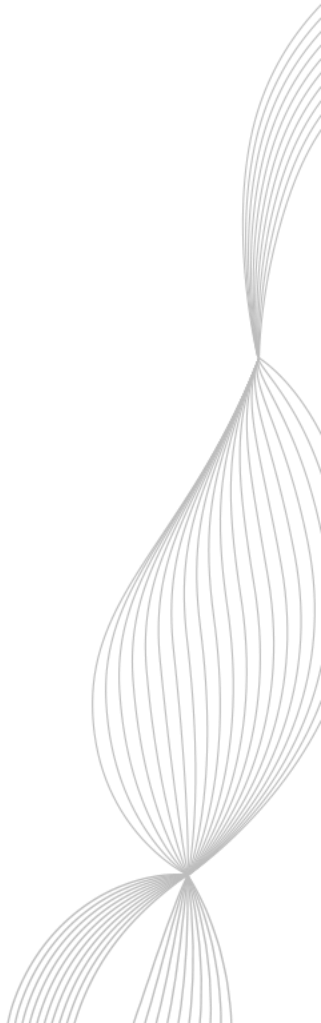
Héctor is on the board of directors with Disability Rights California & the National Disability Rights Network where Héctor provides oversight & accountability of the nation's only legally based advocacy organization established by Congress to protect the rights of all individuals with disabilities in every state and U.S. territories.



Agenda



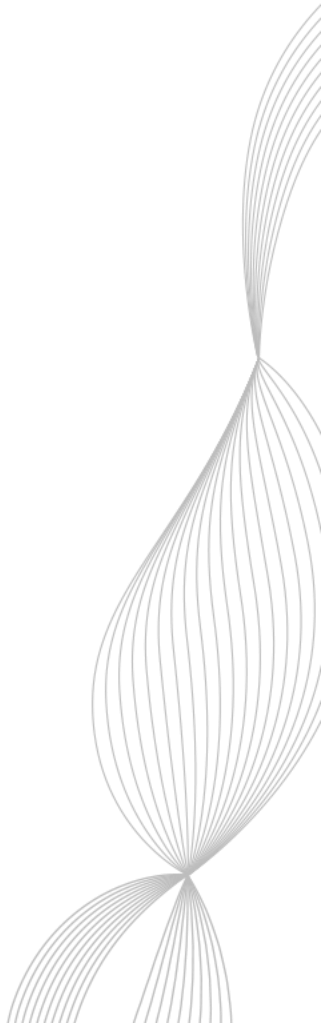
- Background
 - LTSS, HCBS, and Medicaid
 - HCBS workforce and historic workforce crisis
- HCBS Person-centered planning and practices
 - Competencies for person-centered supports
 - Perspectives of person-centered practices in HCBS
 - Barriers and facilitators of choice and control
- Video: Promoting meaningful person-centered practices



Long-term services and supports (LTSS)



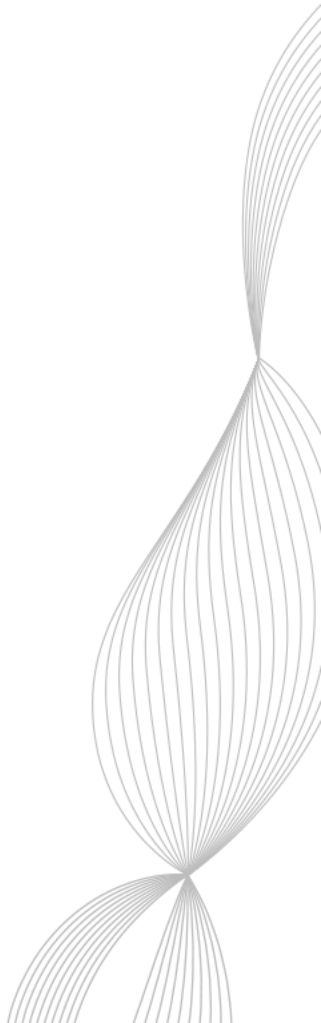
- Health-related and social services to assist people with disabilities and older adults with certain activities
- ~14 million adults in the US are in need of LTSS
- Medicaid is the main payer for LTSS
- Increasingly provided in communities through Home and Community-based Services (HCBS) rather than institutional settings
 - Legal decisions
 - Affordability (lots of unpaid supporters for people who use HCBS)



Home and community-based services (HCBS)



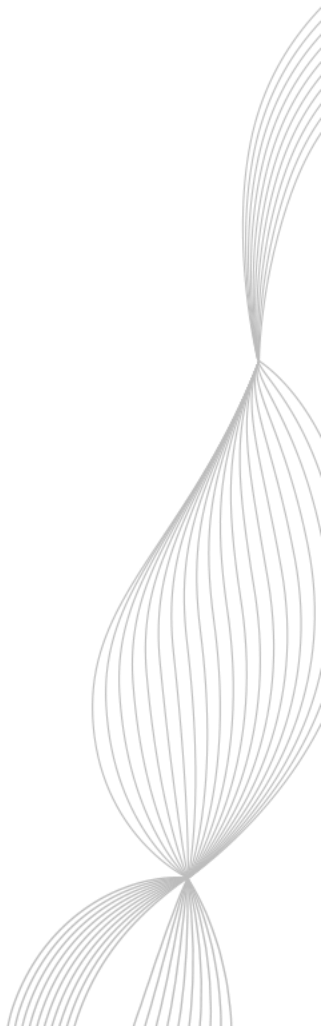
- HCBS provide support for
 - Employment
 - Transportation
 - Homecare/home health
 - Medications
 - Housekeeping
 - In-home therapy (PT, OT, Speech, etc.)
 - Activities of daily living
 - Bathing, dressing, toileting
 - Cooking
 - Day programs
 - Finances
 - Assistive Technology and Home Modifications



Home and community-based services (HCBS)



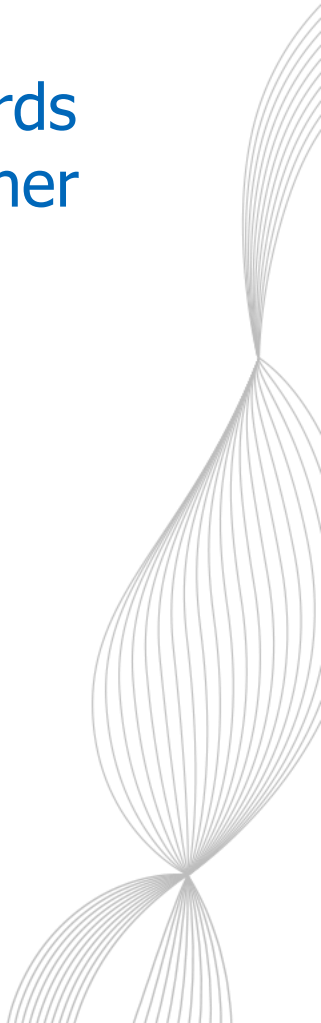
- More than 4.7 million people received Medicaid-funded HCBS in 2018
 - ~2.5 million receive services through optional waivers (1915c, 1115)
 - ~2.2 million through state plans
 - 700,000+ on waiting lists for waiver services
- States have discretion about which populations to prioritize for HCBS waivers
 - Waivers serving people with Intellectual and Developmental Disabilities, Physical Disabilities, and Seniors available in most states
 - Other populations include Psychiatric Disability, Traumatic Brain Injury or Spinal Cord Injury, HIV/AIDS, Medically Fragile



CMS HCBS Final Settings Rule (2014)



- States need to meet criteria by 2023
- Requires every state to ensure that services meet minimum standards for integration, access to community life, choice, autonomy, and other important consumer protections
- Person-centered planning



Person-centered planning and practices



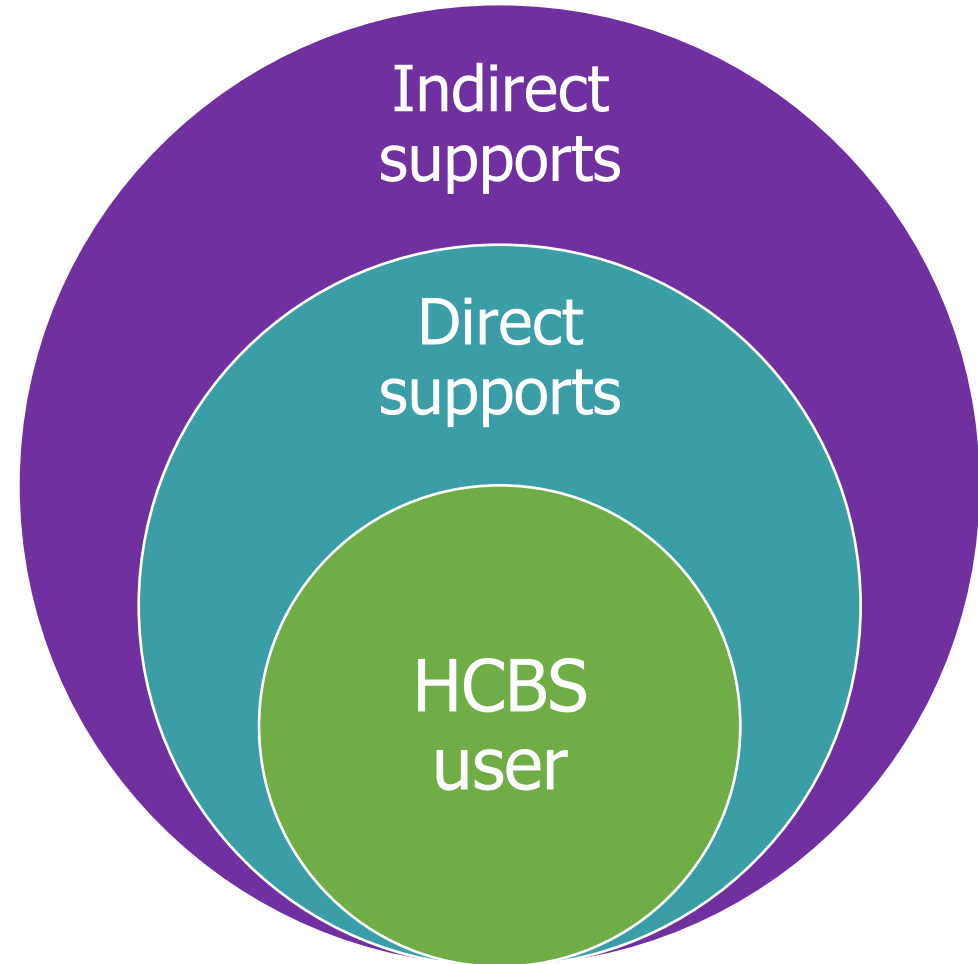
- HCBS Final Settings Rule (2014) from CMS requires person-centered planning in HCBS
- Person-centered planning: the process of creating an individual support plan that incorporates the goals, values, and preferences of the person receiving supports
- Person-centered practices: the delivery of services that promote equitable participation in community activities and assist people working towards their goals



HCBS workforce



- Direct Care Workers
 - Personal Care Workers, Home Health Aides, Nursing Assistants
- PTs/OTs
- Behavioral Specialists
- Family members
- Care Managers
- State coordinators



Workforce Crisis



- 2020 Staff Stability Survey: 43% turnover for DSPs
- PHI National: From 2011 to 2021, there were almost 1.5 million new direct care jobs added
- ANCOR State of America's Direct Support Workforce 2022: 83% of providers are turning away new referrals and 63% are discontinuing programs and services



HCBS measurement & service effectiveness



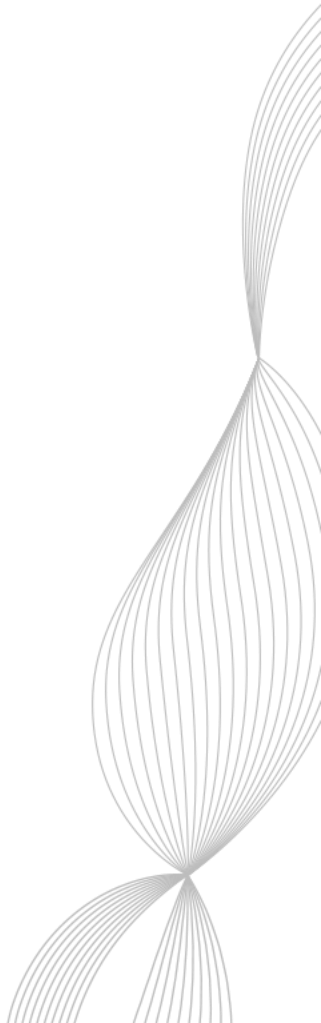
- NCI & NCI-AD 2018 data

91%

Services and supports are helping people have a good life

72%

Services meet all their current needs and goals



Background



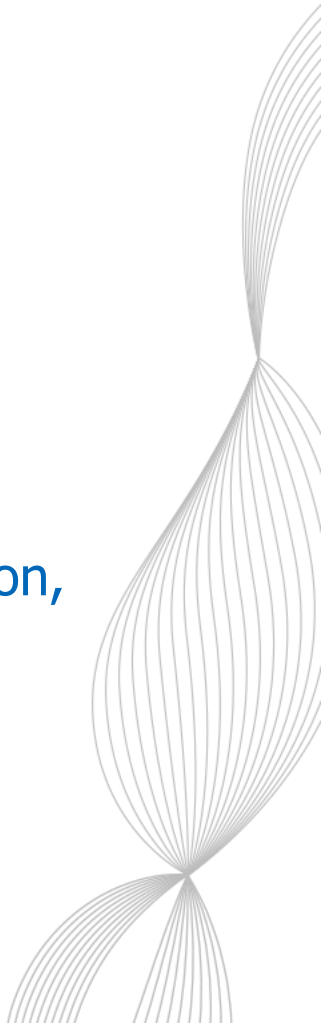
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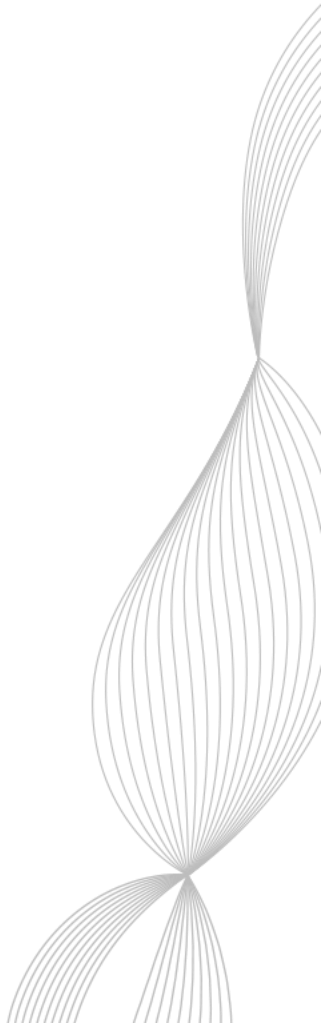
Creating a skilled workforce of HCBS providers



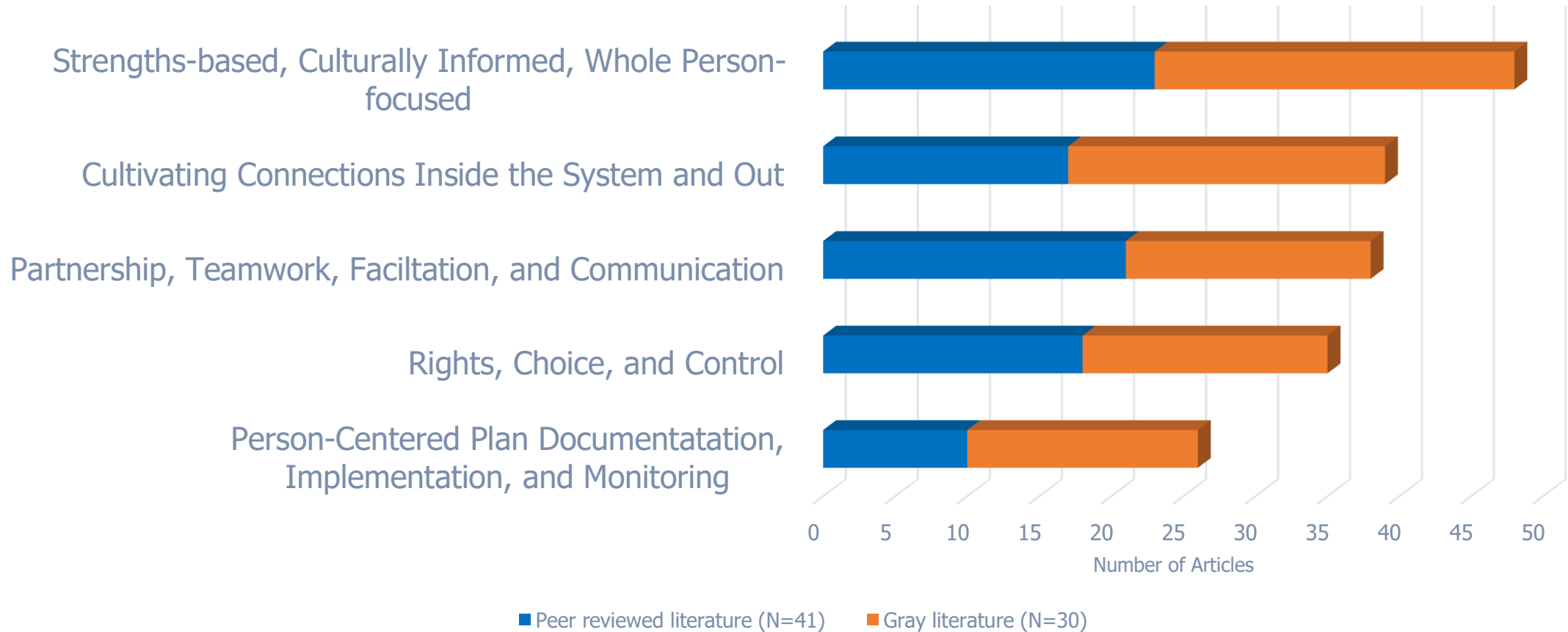
- Aim 1: Identify best practices from literature and research
 - Systematic review of peer-reviewed and grey literature
- Aim 2: Identify specific service delivery skills for home and community-based services based on lived experience
 - Interview home and community-based service providers and users about best practices and skills
 - ~20 constituents across the field of HCBS measure development, coordination, and service delivery
 - ~20 HCBS service participants



NCAPPS framework



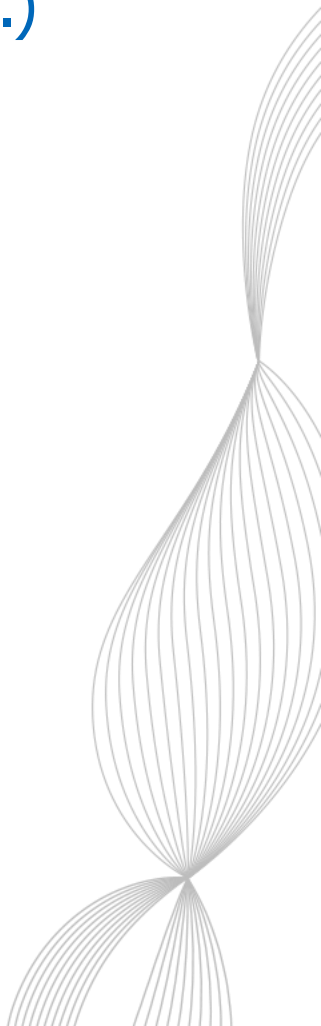
Competencies Identified in Literature



Additional Competency themes



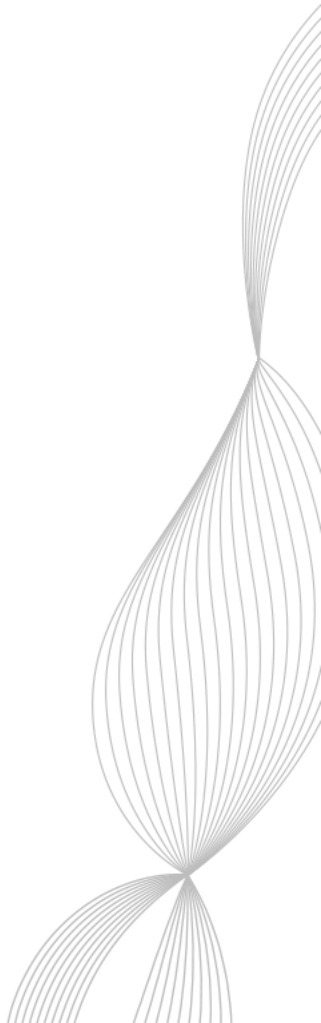
- Supports for healthy aging (fall-prevention, dementia medication, etc.)
- Understanding and supporting nutrition needs
- Working with assistive technology
- Legal/ethical issues
- COVID-19 precautions
- Trauma-informed person-centered practices
- Differences in person-centered competencies across service type, disability, and culture
- Inclusion of family and natural support networks in person-centered planning
- Behavioral and crisis interventions



Recruitment and sample strategies



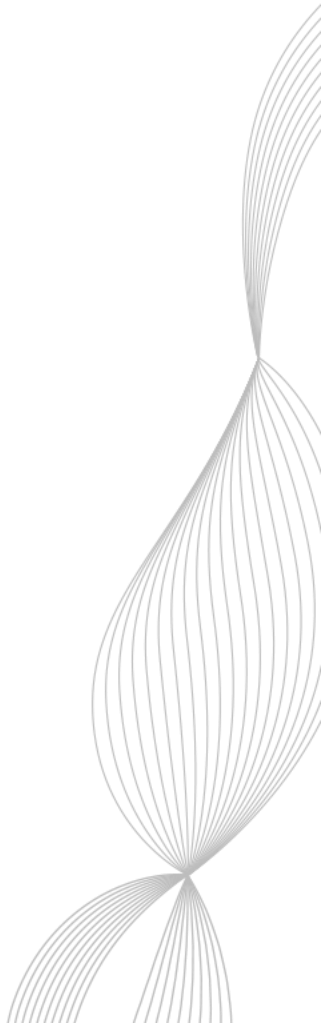
- Quota sampling:
 - Disability (Intellectual and developmental disability, mental health related disability, age related disability, physical disability)
 - Race/ethnicity
 - HCBS setting (Residential, day program, home care. Etc.)
 - HCBS role (Policy leader, provider, recipient)
 - State
- Recruitment:
 - Advisory Council nominations
 - Targeted recruitment to fill quota



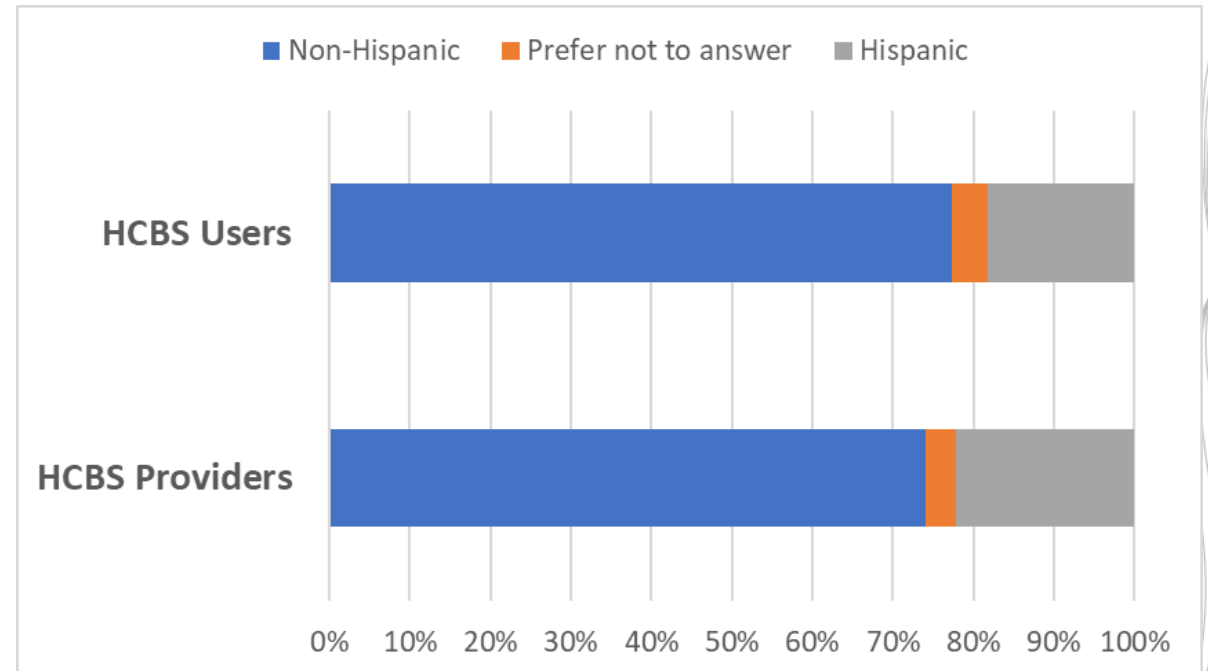
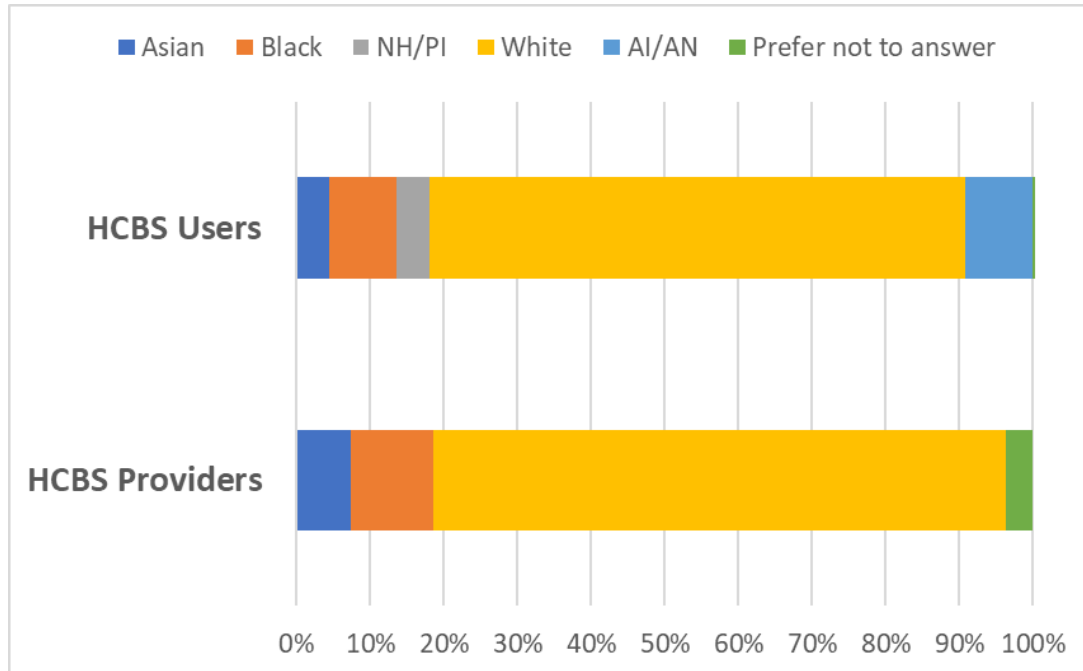
Sample



- 49 participants
 - 27 HCBS providers
 - 22 HCBS users
- Sex
 - 35 female
 - 9 male
 - 5 non-binary
- Average age
 - Providers: 50 years
 - Users: 45 years

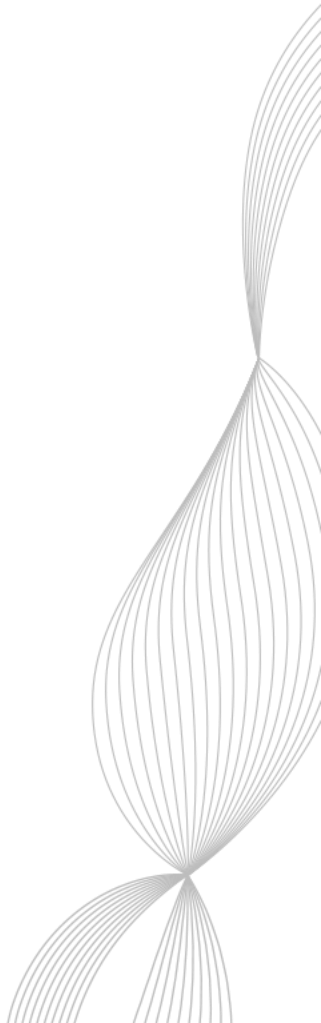
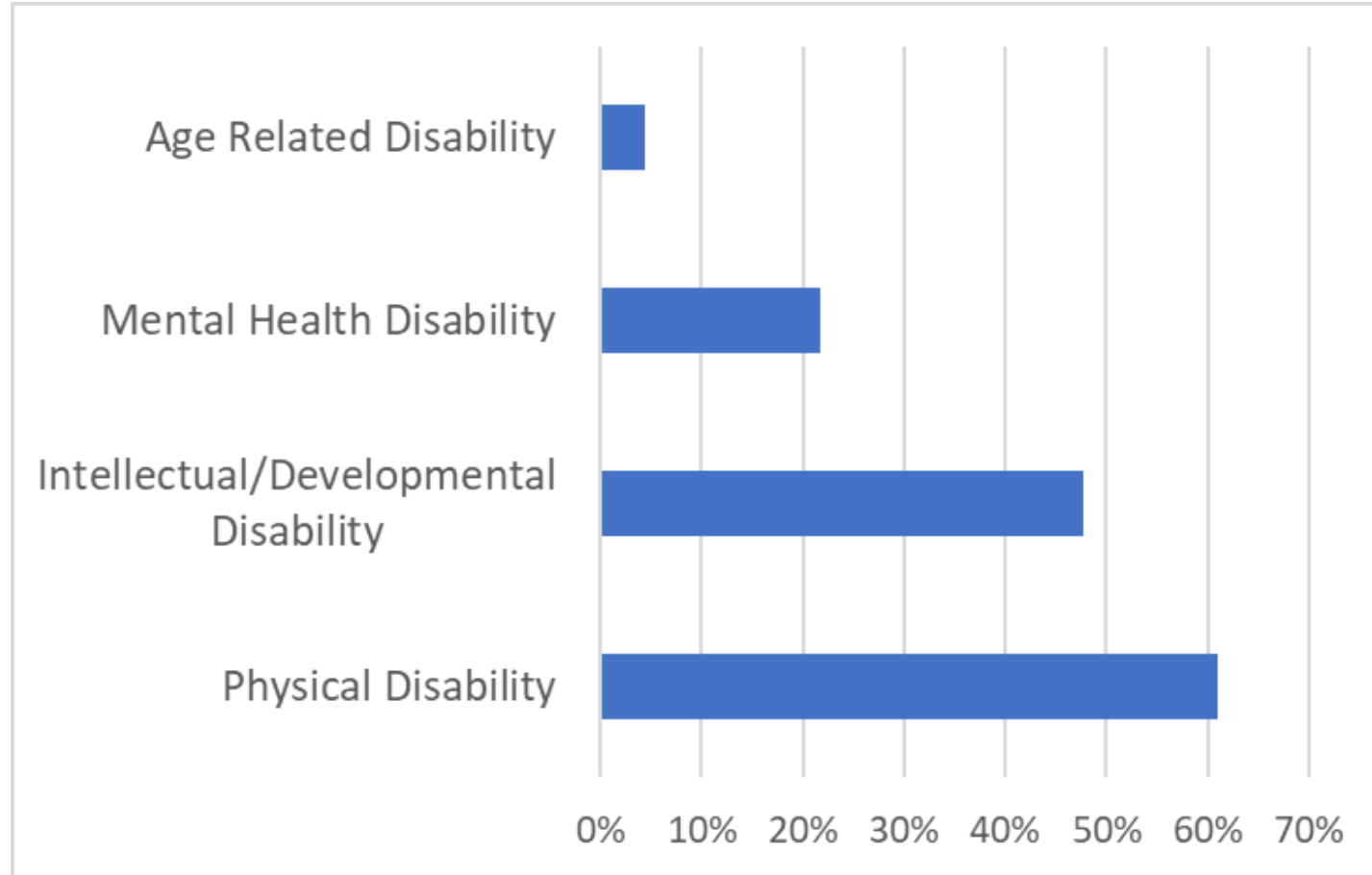


Race/Ethnicity of participants

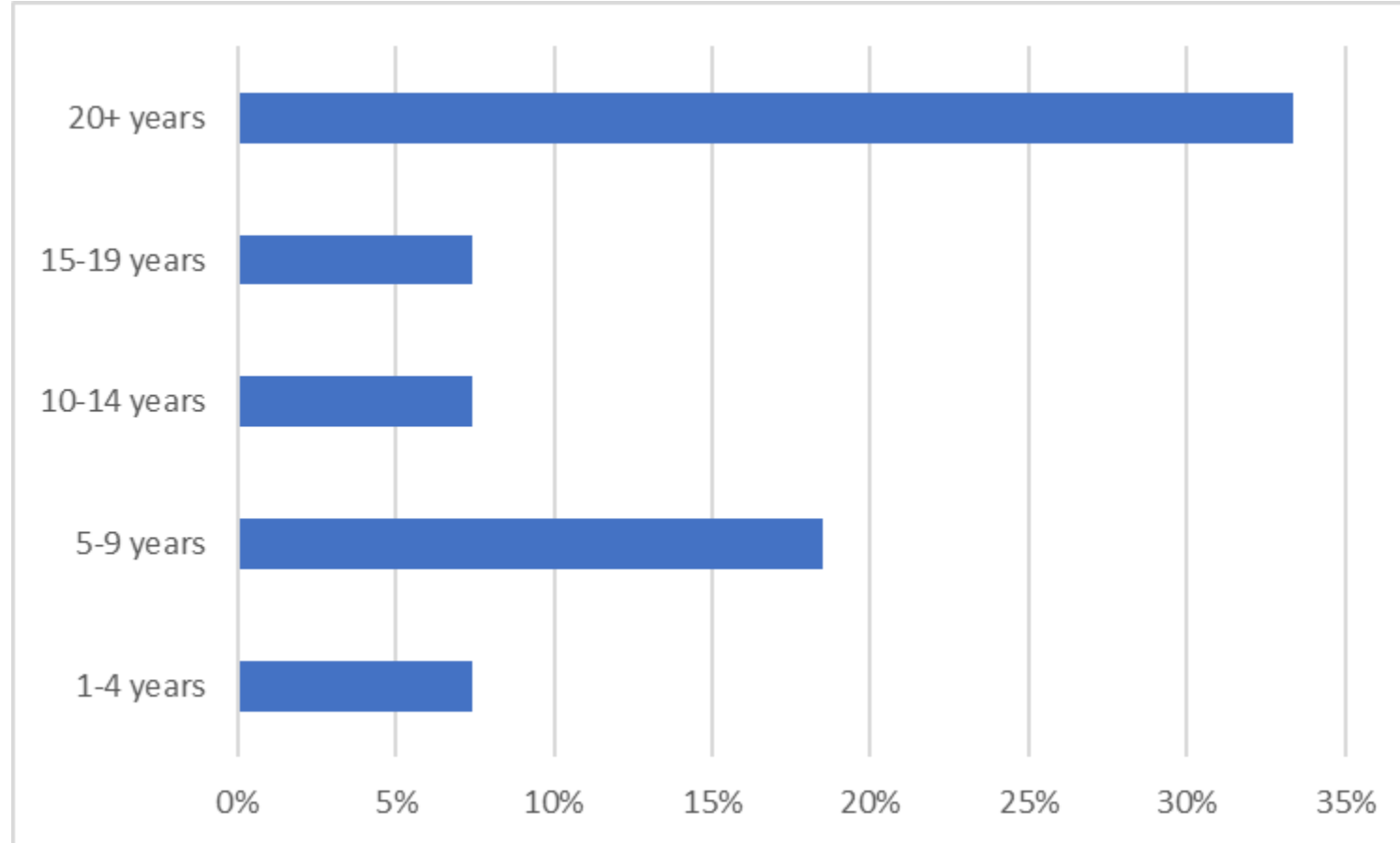


N=22 Users, N=27 Providers

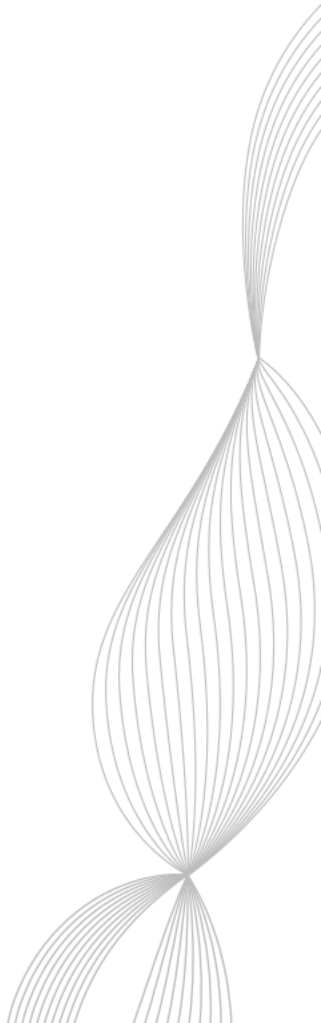
Disability status



HCBS provider years of experience



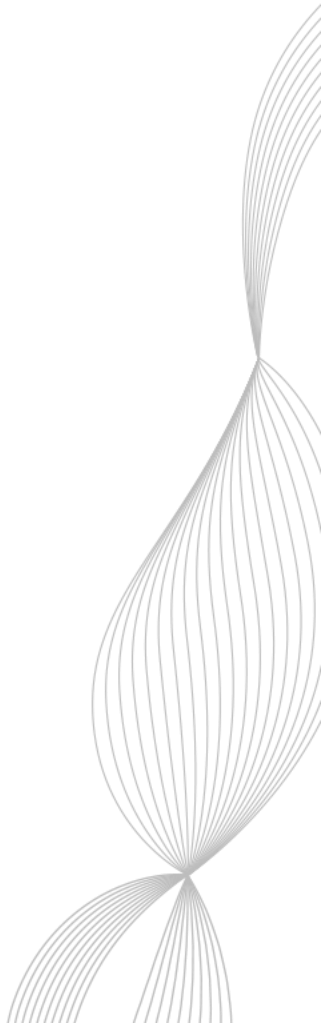
N=27 Providers



Early findings



- Competencies of person-centered practices in HCBS
- Organization and training
- COVID-19 considerations



Perspectives of Person-Centered Practices in HCBS



Respondent	Facilitators of Choice and Control	Barriers to Achieving Choice and Control
<p>Providers and State Leaders of HCBS</p>	<ul style="list-style-type: none"> ▪ Harm reduction ▪ PCP interventions: <ul style="list-style-type: none"> Motivational interviewing ▪ Auditing – documentation ▪ Choice in services and goals ▪ Training 	<ul style="list-style-type: none"> • “Real world” choices are constrained • Organizational constraints • Definitions of choice/control by setting • “Liability” and dignity of risk • "Passing the buck" • High turn-over – workforce crisis • Limited choices by environment
<p>Users of HCBS</p>	<ul style="list-style-type: none"> • Hiring and choosing staff • Transparency of planning and goals • Leading vs. "being a part of" • "Meaningful" and "significant" choice • Choice and control over time, not just activities and goals • Trauma informed • Cultural competency 	<ul style="list-style-type: none"> ▪ “Real world” choices are constrained • Constraints of the service plan • Organizational constraints • Differences of choice/control by setting • “Liability” and dignity of risk • High turn-over – workforce crisis • Quality of services



Organizational or
bureaucratic barriers

"Sometimes services make me feel trapped."
"Services are a barrier to facilitating rights, choice, and control."



Choice and control over
time

What does choice and control mean to you?
"Being able to decide what time I want to get out of bed in the morning, if I want to take a shower or not, what food I want to eat, time I want to go out."



"Meaningful" and
"significant" choice

"I don't get to make choices, but I have input into choices that are available."



Leadership

"My choice, my way" - These are my goals, but I need your help to accomplish them.



Linda A. Hirsch



Tracy L. Brown



Gail M. Hirsch



Kelly A. Hirsch



Michael A. Hirsch



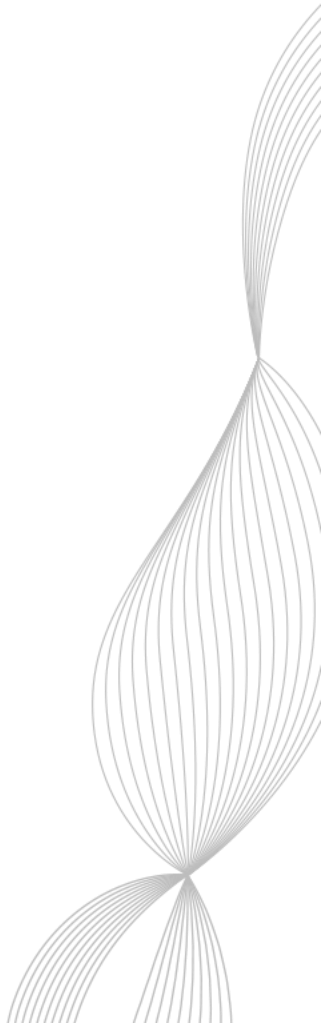
**“IT’S UP TO US, WHAT KIND OF LIFE WE WANT TO LIVE”
PROMOTING MENTORING, PERSON-CENTERED PRACTICES
IN HOME AND COMMUNITY-BASED SERVICE DELIVERY**

June 8, 2017
10:00 AM - 12:00 PM
1000 University Ave, Suite 1000, Berkeley, CA 94702

COVID-19 considerations



- Hiring and retention
- In-person v. virtual
 - Access to technology
 - Adapting to technology
- Vaccination and mask-wearing
 - Choice and control
- Resiliency, charity, and creativity
- Medicaid flexibilities
- From person-centered practices to meeting basic needs



State and Organizational Level Implications



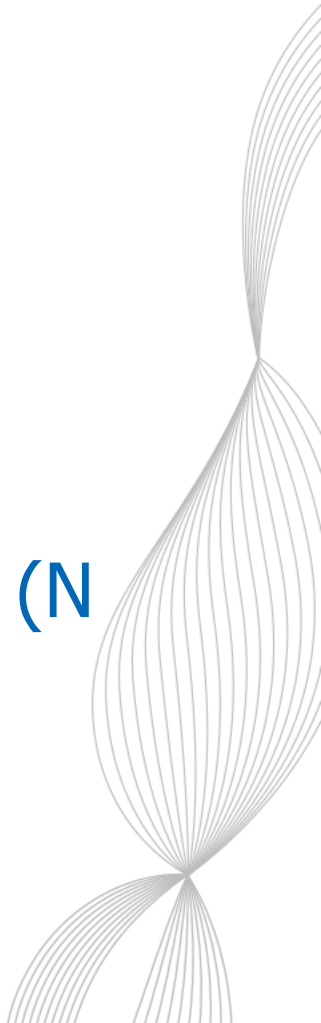
- "Nothing about us without us"
- Medicaid reimbursement reform
- Direct service wage reform
- Systematic and formal person-centered training and practices
- Systematic data collection and analysis of person-centered outcome measures
- Public reporting and system transparency



HCBS organization case studies



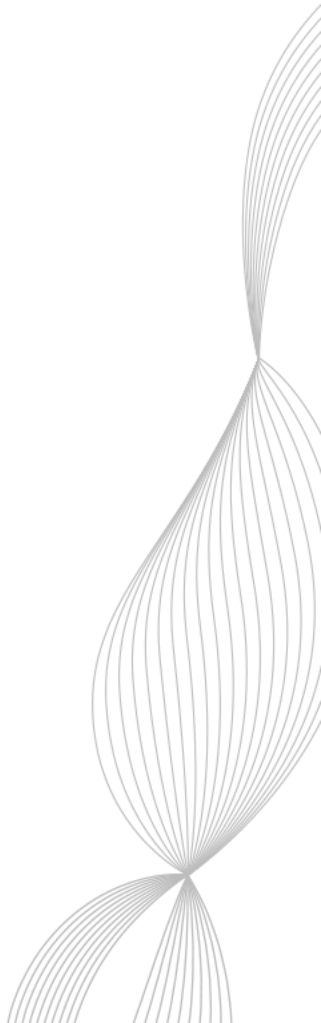
- Research Aims:
 1. Identify how HCBS leaders and practitioners deliver HCBS person-centered planning and practices.
 2. Identify how HCBS participants engage and experience person-centered planning and practices.
- 6-8 organizations
- Interviews: organization leaders, DSP's, service participants (N depends on the size of the organization)
- Review of training and documentation materials



Thank you!



- Tonie Sadler – tsadler@sralab.org
- Lindsay Dubois – ldubois@sralab.org





NARRTC

Shirley Ryan
Abilitylab



NCAPPS

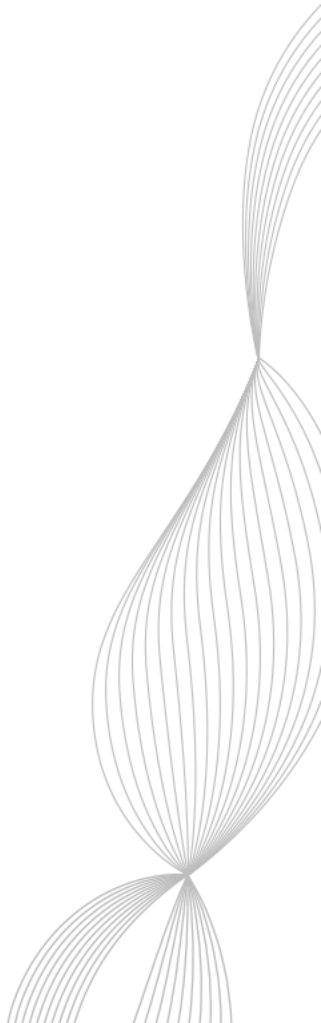
Future Directions and Knowledge Translation



KT projects of HCBS grant



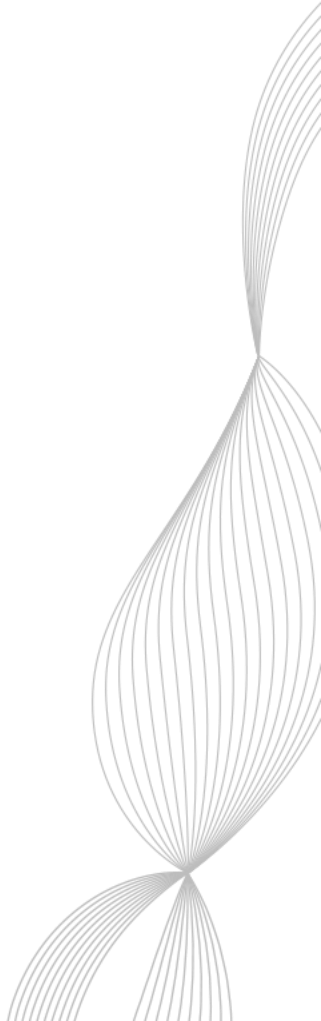
- Dissemination
 - Social media posts and campaigns
 - Policy/issue briefs
 - Newsletter
- Utilization
 - Provider comparison website
 - Training materials for intervention project (2023)
- Training
 - Webinars
 - Podcasts
 - Conference Presentations



Universal design approaches for research



- Easy read informed consent
- Vignettes during interviews
- Knowledge translation activities:
 - Social media
 - HCBS Podcast for diverse and broad audience
 - Webinars and conferences
 - Newsletters
 - Issue Briefs



IRB Easy Read



Key information about this research study:

The information below is a summary of this study. This can help you decide whether to be a part of this study.



You will be asked questions that will help the research team prioritize outcomes to include in a new person-centered measure of HCBS. These questions will take place on a videoconference call with other Advisory Council members as part of a focus group.



A research study has potential **benefits** and **risks**. For this focus group, the **main risk** is describing experiences with services that are potentially upsetting to talk about.



The **main benefit** of participating in the study is getting to help develop a new way to measure experiences people have when receiving home and community-based services.



Interview vignettes



- Interview question: Do the people who provide your services partner with other companies or organizations to provide your services?
- Vignette:
 - Angel receives personal care services from HCBS Organization 2. However, Angel has a goal to get a job, and has requested a job coach. HCBS Organization 2 does not have any job coaches on staff, and so HCBS Organization 2 reaches out to another organization to partner in offering job coaching to Angel. Does your organization partner with other organizations to provide your services? Can you tell me more about that?



Inside HCBS Podcast



Center for Rehabilitation Outcomes Research, Shirley Ryan AbilityLab is with Carla Giannotti and Kenny Giannotti. ...

September 15, 2021 · 🌐

We are so excited to share with you the inaugural episode of our podcast, Inside HCBS! The CROR team created this podcast series with the hope that it can be an informative resource about all things home and community-based services for our listeners.

Our first episode, "Kenny's World: Person-Centered Planning in Practice" is about Kenny and his provider agency, Marrakech, and how they partnered to make the necessary changes to Kenny's services so that they meet his goals and preferences. We explore themes related to paternalism and choice and control, community inclusion, and what success looks like when provider agencies deliver services and supports in a person-centered way.

Listen to the podcast to hear a wide-ranging and honest conversation between Kenny, Heather LaTorra, CEO of Marrakech, Inc., and Tanya Richmond, Partner at Support Development Associates.

You can listen to the podcast here:

Spotify: <https://open.spotify.com/show/2PFGrc0rGRDqWwOeHaUJ0e>

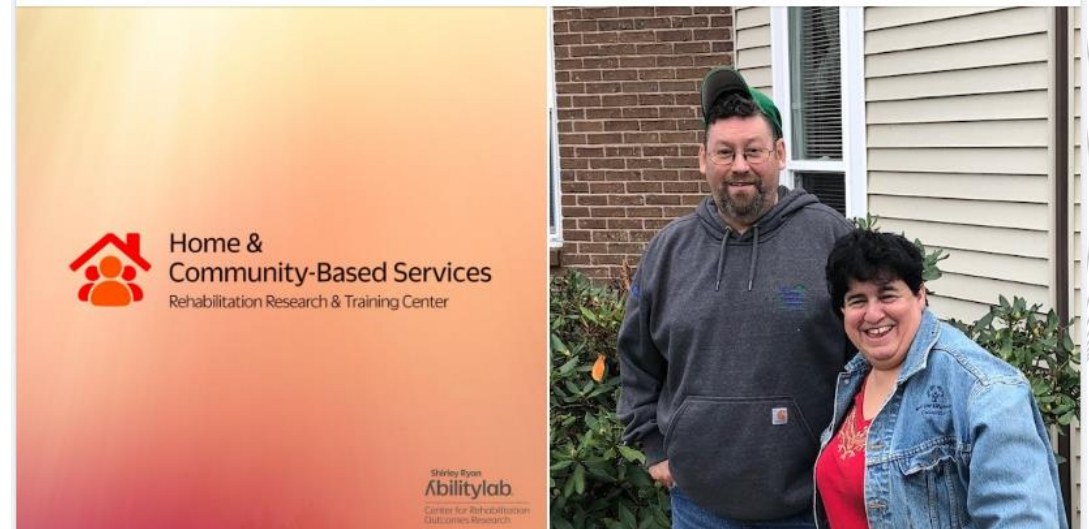
Apple Podcasts: <https://podcasts.apple.com/.../inside-hcbs/id1585204849...>

Google Podcasts: <https://podcasts.google.com/.../aHR0cHM6Ly9hbmNob3luZm0vc...>

Anchor: <https://anchor.fm/cror>

And find the transcript of the episode here:

<https://docs.google.com/.../1RD3oHX6J9oi8qDqS8Udp7NS.../edit>



HCBS Quality Matters Newsletter



Issue Brief



MENU

SEARCH

PATIENT PORTAL | PAY A BILL

Disability Models on Person-Centeredness in Home and Community-Based Services

SHARE    

MARCH 14, 2022

Download

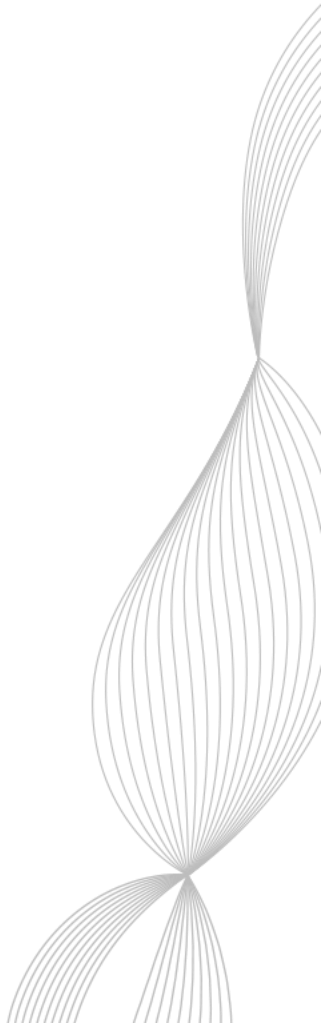
HCBS Disability Models and Person-Centeredness Brief.pdf



Opportunities for collaboration



- HCBS Post-doctoral fellowship
- Internships



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