

**“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**

September 22, 2022



NCAPPS



Home &  
Community-Based Services  
Rehabilitation Research & Training Center



# Welcome to Today's Webinar



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Project Manager

Thank you for joining us to learn about rights, choice, and control and how these critical elements can be improved and fully integrated into service delivery practices.

Today's webinar is co-sponsored by the National Center on Advancing Person-Centered Practices and Systems (NCAPPS) and the Center for Rehabilitation Outcomes Research (CROR).

NCAPPS is funded by the Administration for Community Living (ACL) and Centers for Medicare & Medicaid Services (CMS).

Any personal opinions shared during the presentation are not the opinions of CMS or ACL.

NCAPPS webinars are free and open to the public.

The goal of NCAPPS is to promote systems change that makes person-centered principles not just an aspiration but a reality in the lives of people across the lifespan.





# Webinar Logistics

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- Participants will be muted during this webinar. You can use the **chat** feature in Zoom to post questions and communicate with the hosts.
- Toward the end of the webinar, our speakers will have an opportunity to **respond to questions** that have been entered into **chat**.
- The webinar will be live captioned in English and live interpreted in Spanish.
  - Live English captions can be accessed by clicking the “CC” button at the bottom of your Zoom screen.
  - Live Spanish interpretation can be accessed by clicking the “interpretation” button at the bottom of your Zoom screen (world icon).
- This live webinar includes polls and evaluation questions. Please be prepared to interact during polling times.



# Feedback and Follow-Up

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- After the webinar, you can send follow-up questions and feedback about the webinar to [NCAPPS@hsri.org](mailto:NCAPPS@hsri.org).

(Please note that this email address is not monitored during the webinar.)

- The recorded webinar, along with a pdf version of the slides and a Plain Language summary, will be available within two weeks at [NCAPPS.acl.gov](http://NCAPPS.acl.gov). We will also include questions and responses in the materials that are posted following the webinar.

# Who's Here?

**“In what role(s) do you self-identify? Select all that apply.”**

1. Person with a disability/person who uses long-term services and supports
2. Family member/loved one of a person who uses long-term services and supports
3. Self-advocate/advocate
4. Peer specialist/peer mentor
5. Social worker, counselor, or care manager
6. Researcher/analyst
7. Community or faith-based service provider organization employee
8. Government employee (federal, state, tribal, or municipal)

# Meet Our Speakers



**LINDSAY DUBOIS**



**TONIE SADLER**



**BATHEY FONG**



**REVECA TORRES**



**HECTOR MANUEL RAMÍREZ**



# 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

Bathey Fong, Reveca Torres, and Héctor  
Ramírez

Lindsay DuBois and Tonie Sadler



# Agenda



- Background
- Project goals
- Project methods
- Project results
- Panel discussion

# 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)



# Home and community-based services (HCBS)



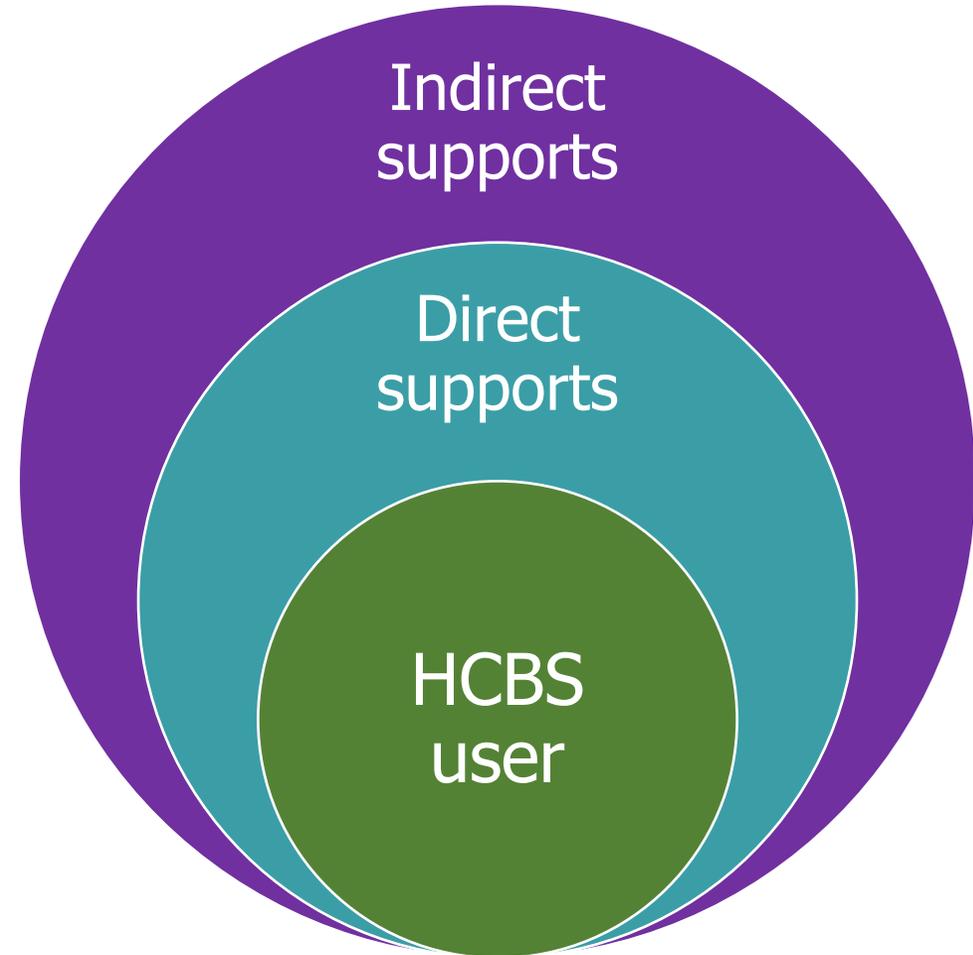
HCBS provide support for:

- Employment
  - Transportation
  - Homecare/home health
    - Medications
    - Housekeeping
    - In-home therapy (PT, OT, Speech, etc.)
  - Activities of daily living
    - Bathing, dressing, toileting
    - Cooking
  - Finances
  - Assistive Technology and Home Modifications
- More than 4.7 million people received Medicaid-funded HCBS in 2018
  - Each state has its own system and decides which populations to offer HCBS waivers to

# HCBS workforce



- Direct Care Workers
  - Personal Care Workers, Home Health Aides, Nursing Assistants
- PTs/OTs
- Behavioral Specialists
- Family members
- Care Managers
- DCW supervisors
- 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
- PHI National: From 2020 to 2030, estimated 7.9 million total job openings in direct care

# Person-centered federal requirements



- CMS HCBS Final Settings Rule (2014)
  - 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

# HCBS measurement & service quality



○ NCI & NCI-AD 2018 data

**91%**

Services and supports are helping people have a good life

**89%**

Staff have the right training to meet their needs

**72%**

Services meet all their current needs and goals

# Creating a skilled workforce of HCBS providers



- Goal: Identify specific service delivery skills for home and community-based services
  - 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
  - Conduct case studies within HCBS organizations examining person-centered practice delivery

# Recruitment and sample strategies



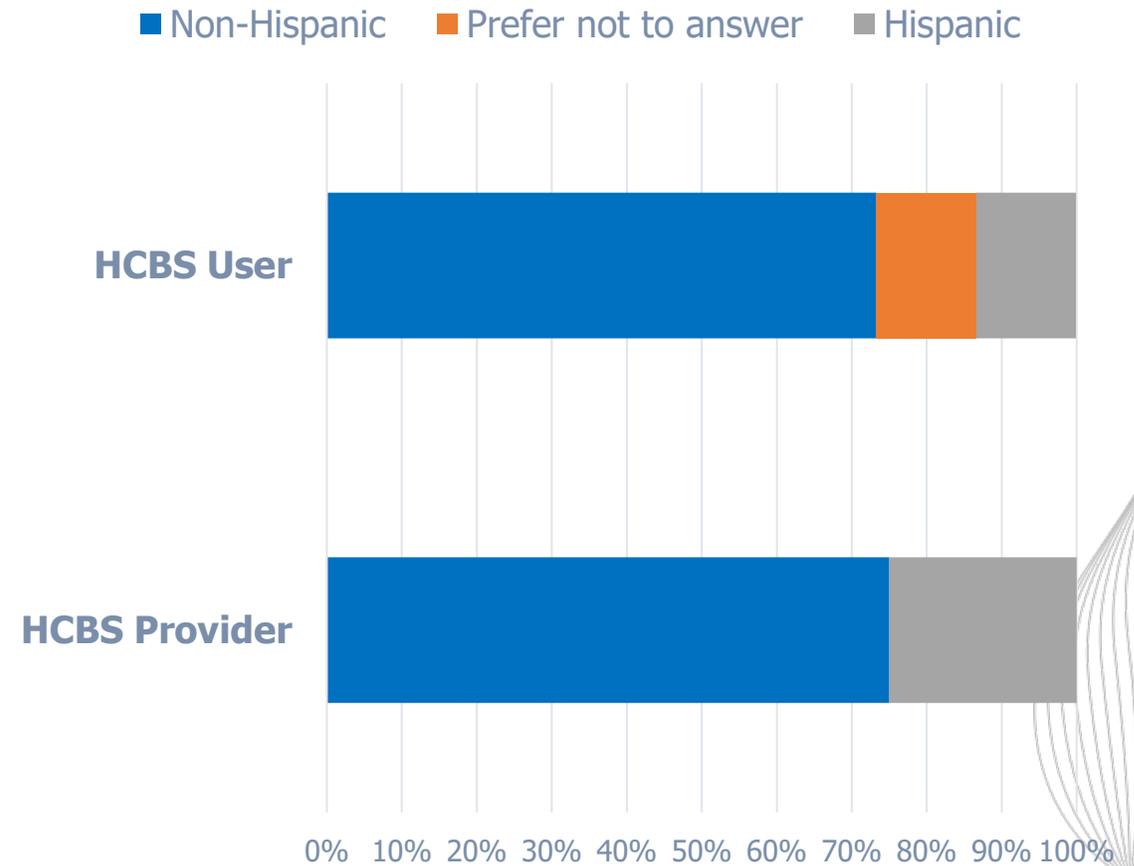
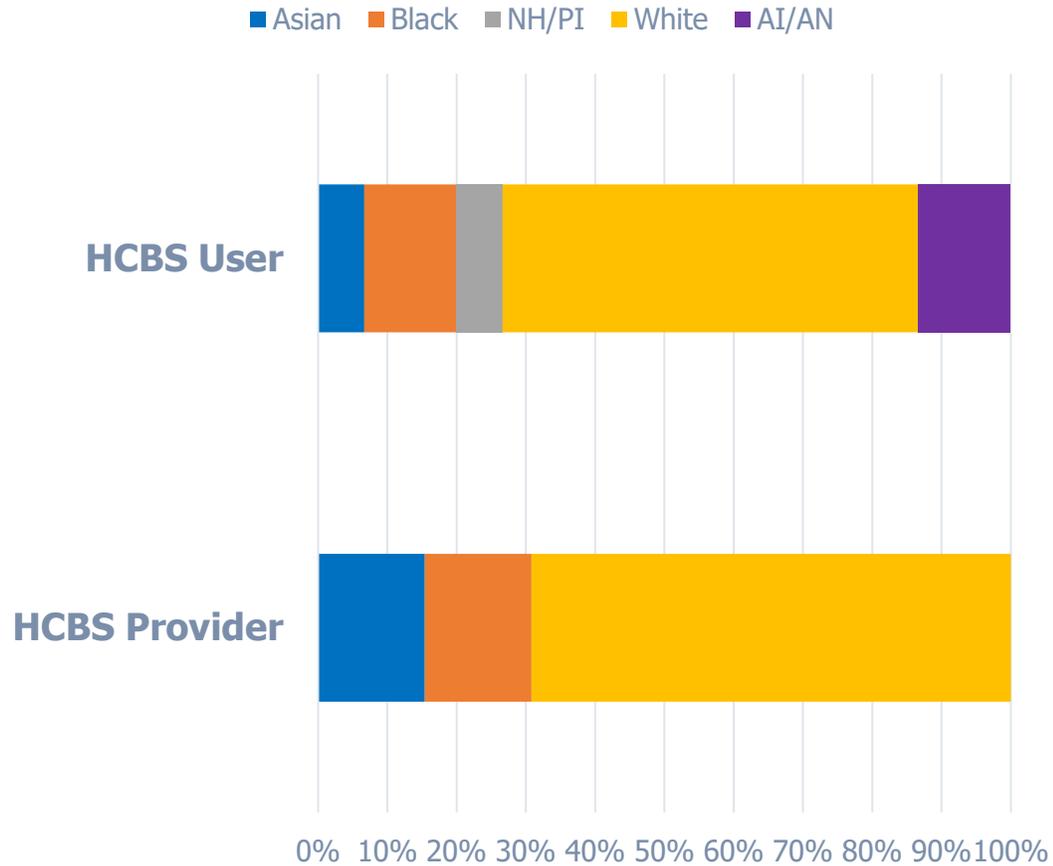
- Quota sampling:
  - Disability (Intellectual and developmental disability, mental health related disability, age related disability, physical disability)
  - Race/ethnicity
  - HCBS setting (Residential, day program, home care. Etc.)
  - HCBS role (Policy leader, provider, recipient)
  - State
- Recruitment: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

# Sample (as of 9-9-2022)



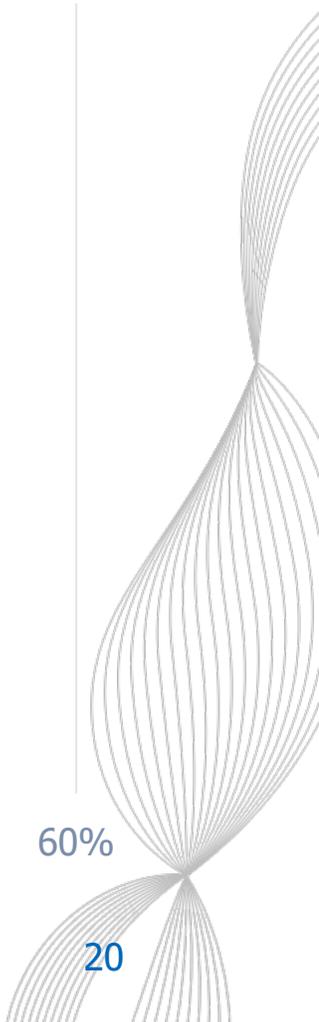
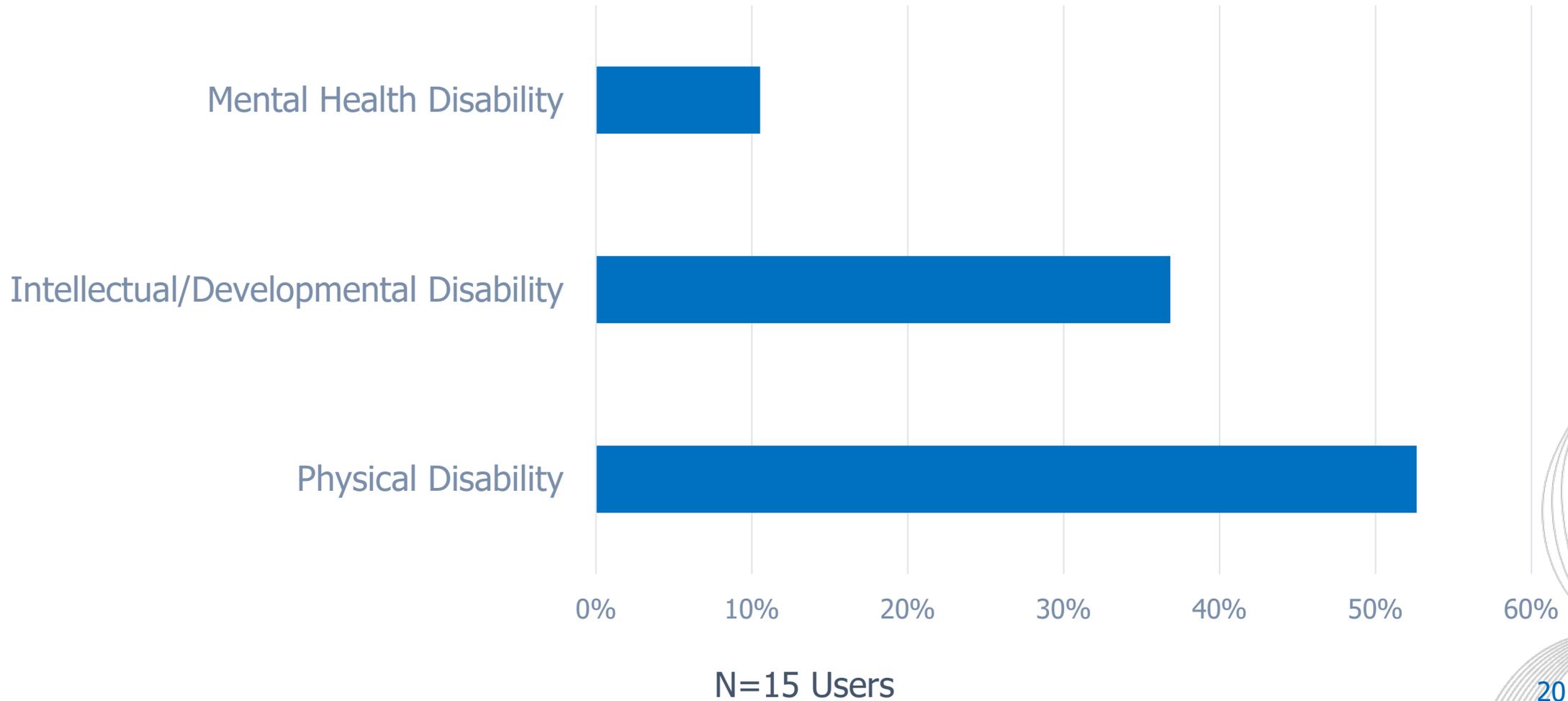
- 27 participants (12 HCBS providers, 15 HCBS users) with complete data
- 19 female, 5 male, 3 non-binary
- Average age
  - Providers: 49
  - Users: 44

# Race/Ethnicity of participants

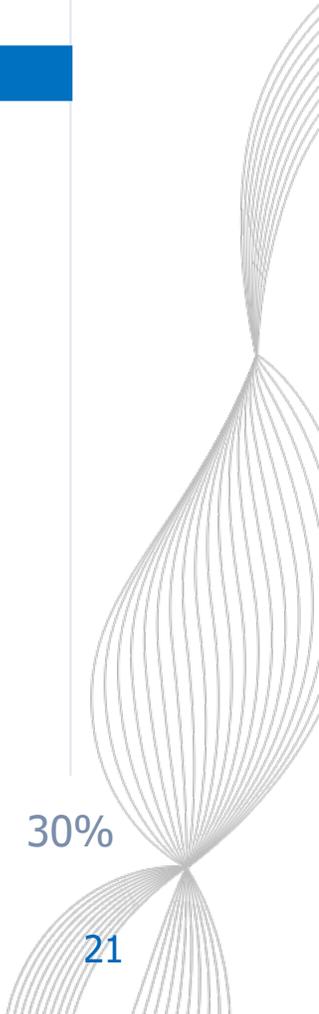
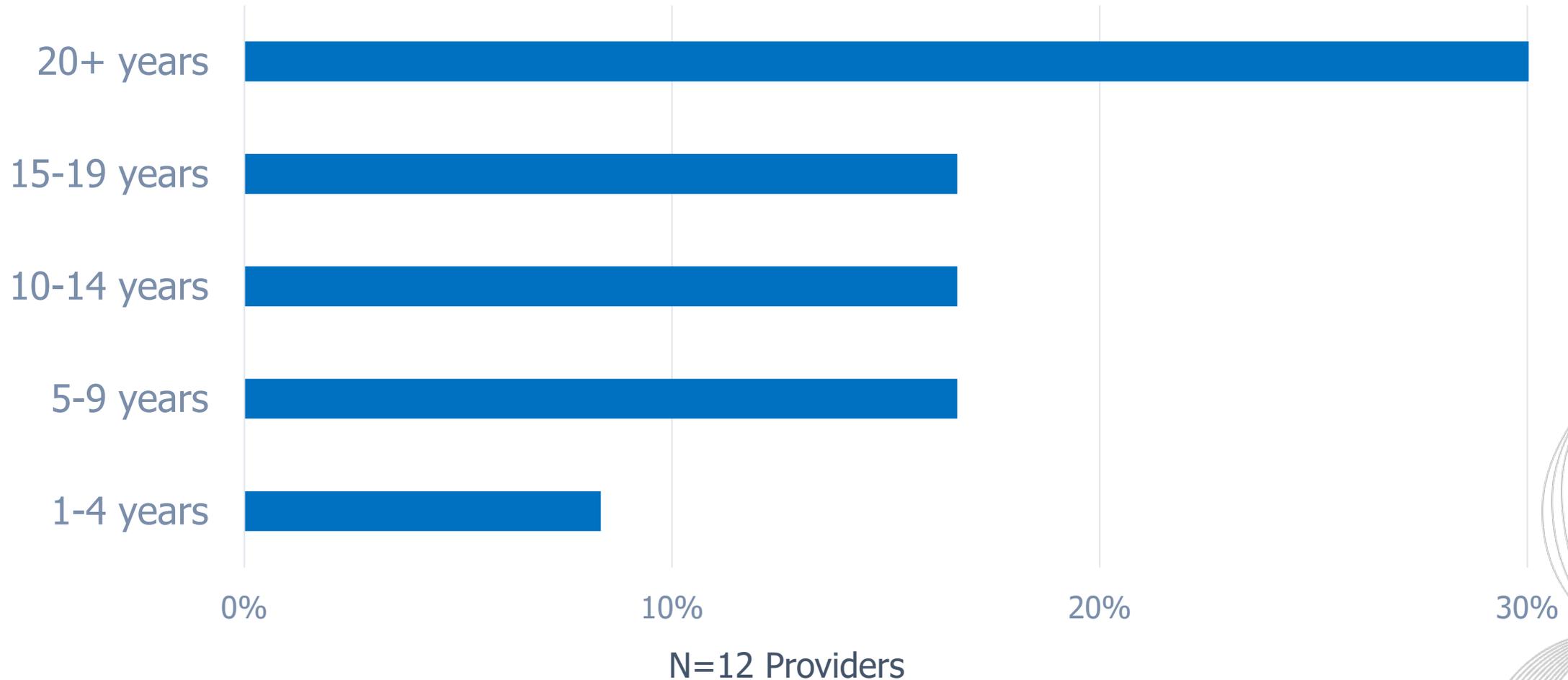


N=15 Users, N=13 Providers

# Disability status



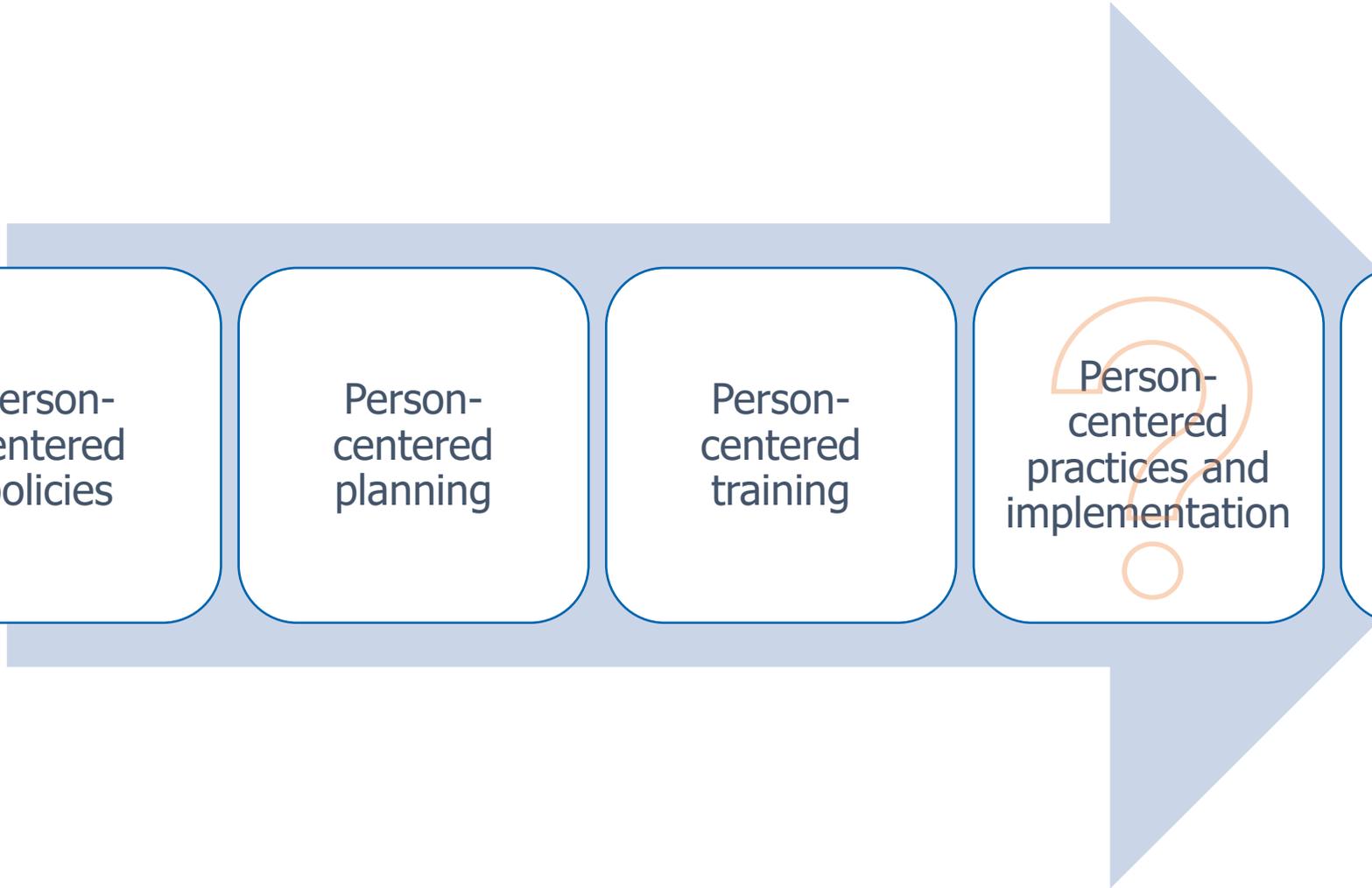
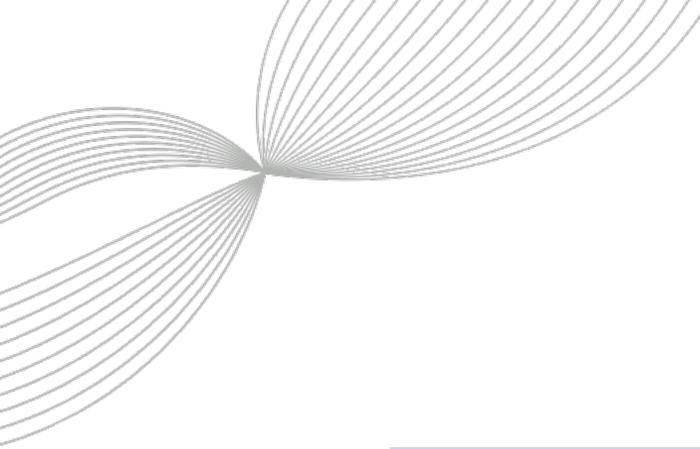
# HCBS Provider Years of Experience



# Early findings



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



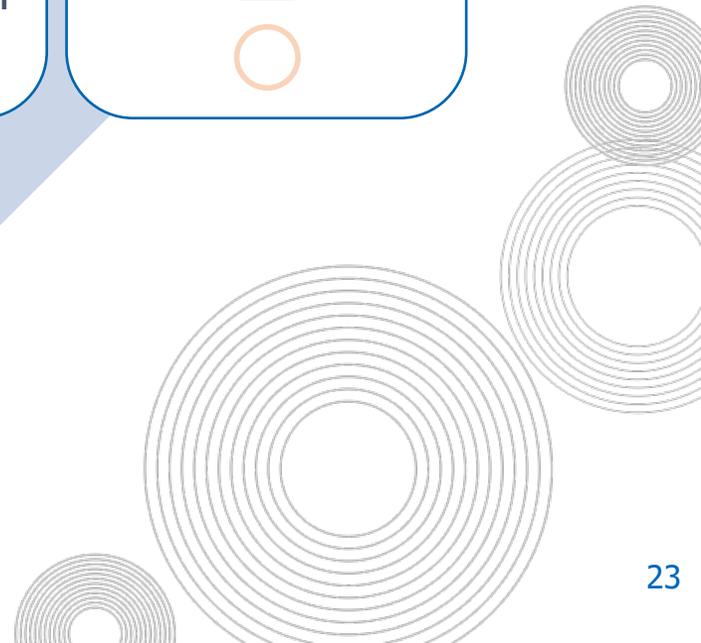
Person-centered policies

Person-centered planning

Person-centered training

Person-centered practices and implementation

Person-centered outcomes



# Person-centered practices in HCBS: Choice, control and dignity of risk



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

|   |  |  |
|---|--|--|
|    | <p>Organizational or bureaucratic barriers</p> | <p>"Sometimes services make me feel trapped."<br/>         "Services are a barrier to facilitating rights, choice, and control."</p>   |
|    | <p>Choice and control over time</p>            | <p>What does choice and control mean to you?<br/>         "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."</p> |
|    | <p>"Meaningful" and "significant" choice</p>   | <p>"I don't get to make choices, but I have input into choices that are available."</p>  |
|  | <p>Leadership</p>                              | <p>"My choice, my way" - These are my goals, but I need your help to accomplish them.</p>  |

# Organization, training, and staffing considerations



|                     |  |
|---------------------|--|
| <b>Organization</b> | <ul style="list-style-type: none"><li>• Person-centered practices implemented but not formalized</li><li>• Service reimbursement rates (1:1)</li><li>• Administrative barriers and waitlists</li><li>• Urban v. rural access</li><li>• Interorganizational collaboration</li></ul> |
| <b>Training</b>     | <ul style="list-style-type: none"><li>• Lack of consistent training</li><li>• State and organization training continuity and variation</li><li>• Formalized person-centered training</li><li>• Use of interventions</li></ul>  |
| <b>Staffing</b>     | <ul style="list-style-type: none"><li>• High turn-over and low-wages</li><li>• COVID-19</li><li>• Family care provider restrictions</li><li>• Passion and creativity</li><li>• Career advancement opportunities</li></ul>  |

# COVID-19 considerations

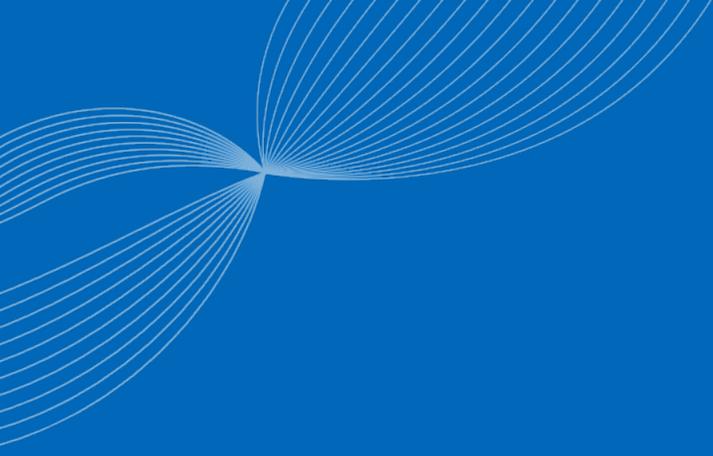


- Hiring and retention
- In-person v. virtual
  - Access to technology
  - Adapting to technology
- Vaccination and mask-wearing
  - Choice and control
- Resiliency, charity, and creativity
- Medicaid flexibilities
- From person-centered practices to meeting basic needs

# Next steps: 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!

<https://www.sralab.org/research/labs/CROR/projects/home-and-community-based-services>

Contact us with any questions!  
Tonie Sadler (tsadler@sralab.org)  
Lindsay DuBois (ldubois@sralab.org)



# Real-Time Evaluation Questions

- Please take a moment to respond to these six evaluation questions to help us deliver high-quality NCAPPS webinars.
- If you have suggestions on how we might improve NCAPPS webinars, or if you have ideas or requests for future webinar topics, please send us a note at [NCAPPS@hsri.org](mailto:NCAPPS@hsri.org)

# Real Time Evaluation Questions

- 1. Overall, how would you rate the quality of this webinar?**
- 2. How well did the webinar meet your expectations?**
- 3. Do you think the webinar was too long, too short, or about right?**
- 4. How likely are you to use this information in your work or day-to-day activities?**
- 5. How likely are you to share the recording of this webinar or the PDF slides with colleagues, people you provide services to, or friends?**
- 6. How could future webinars be improved?**

# Thank You.

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[ncapps.acl.gov](https://ncapps.acl.gov)

NCAPPS is funded and led by the Administration for Community Living and the Centers for Medicare & Medicaid Services and is administered by HSRI.

The content and views expressed in this webinar are those of the presenters and do not necessarily reflect that of Centers for Medicare and Medicaid Services (CMS) or the Administration for Community Living (ACL) .

