What's Going on in Person-Centered Practices?

Overview of Current Resources, Practices, and Recommendations

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Center for Rehabilitation Outcomes Research

AGENDA

- Introduction to project
- Content background
- What we did for this project
- What we found from this project
  - Person-centered competencies
  - Barriers to implementation of person-centered competencies
- What's next for the field
- Other ways Shirley Ryan AbilityLab is helping this work

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Study Background

- Center for Rehabilitation Outcomes Research at Shirley Ryan AbilityLab (CROR) receives five-year grant for Home and Community-Based Services (HCBS) Rehabilitation Research and Training Center (RRTC)

- **Funding**: National Institute on Disability, Independent Living, and Rehabilitation Research (US Department of Health and Human Services)

The Shirley Ryan AbilityLab Team

- Allen Heinemann, PhD, Project Director
- Bridgette Schram, PhD, Project Manager
- John Abbate, MSW, Research Assistant
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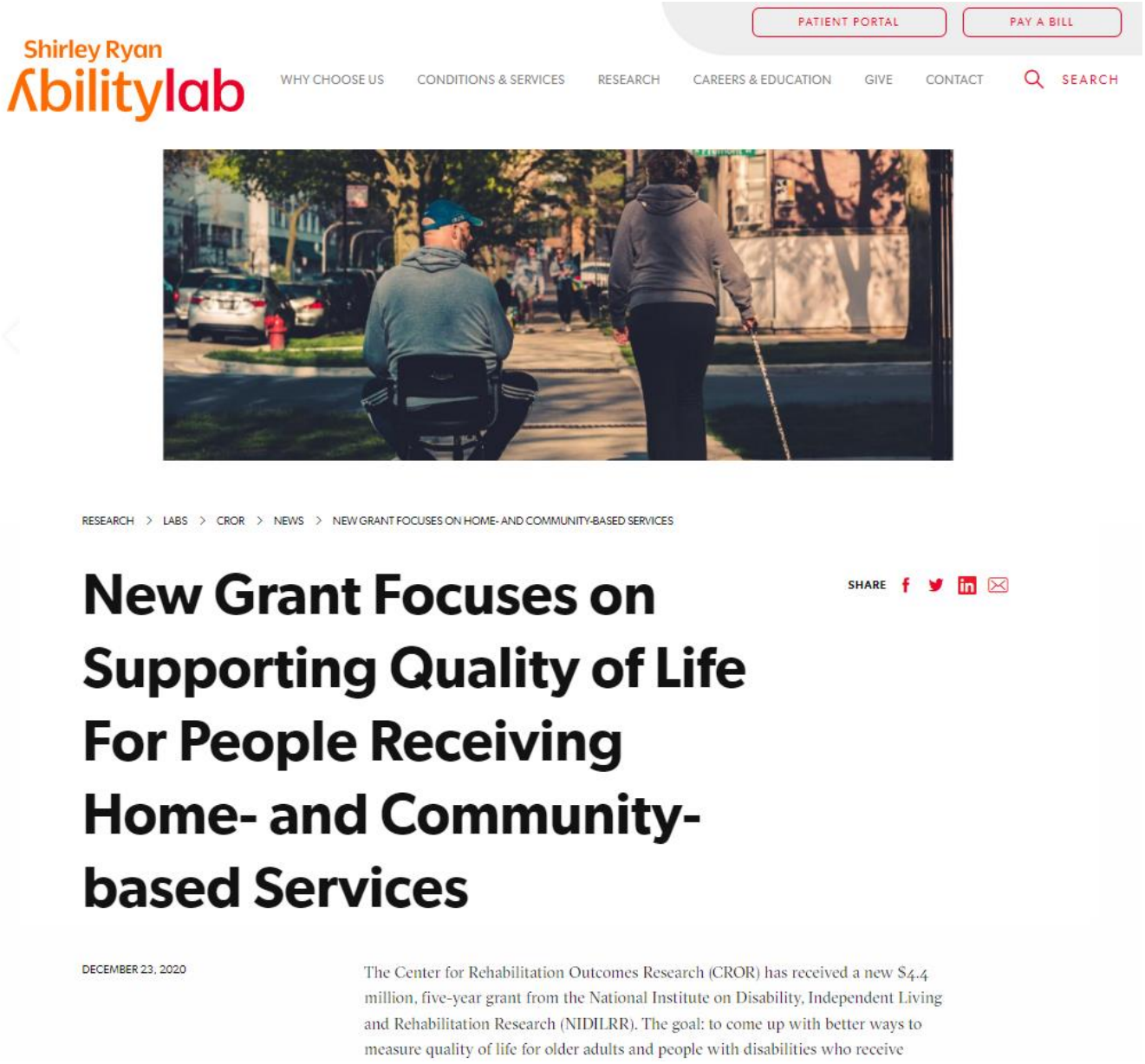
- Jacqueline Kish, PhD, OTR/L, Post-Doctoral Fellow
- Elise Olsen, Research Assistant
- Niveda Tennety, Research Coordinator



PATIENT PORTAL PAY A BILL

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WHY CHOOSE US CONDITIONS & SERVICES RESEARCH CAREERS & EDUCATION GIVE CONTACT SEARCH

RESEARCH > LABS > CROR > NEWS > NEW GRANT FOCUSES ON HOME- AND COMMUNITY-BASED SERVICES

SHARE

New Grant Focuses on Supporting Quality of Life For People Receiving Home- and Community-based Services

DECEMBER 23, 2020

The Center for Rehabilitation Outcomes Research (CROR) has received a new $4.4 million, five-year grant from the National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR). The goal: to come up with better ways to measure quality of life for older adults and people with disabilities who receive

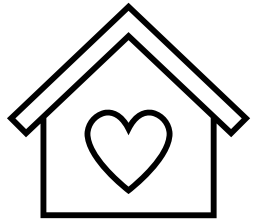
Home and Community-Based Services (HCBS)

Personal care:

- Dressing
- Bathing
- Toileting
- Eating

Help with daily tasks:

- Cleaning
- Grocery shopping
- Meal prep and/or delivery
- Running errands



Home health care and therapy:

- Physical Therapy
- Occupational Therapy
- Speech Therapy

Person-Centered Planning and Practices

- **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

National Center on Advancing Person-Centered Practices and Systems

Research Projects

Project 1

- Develop and test person-centered outcome measures (non-medical) for HCBS

Project 2

- Identify best practices and specific service-delivery skills for HCBS

Project 3

- Develop and test training that improves the skills of providers who deliver HCBS

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NIDILRR
National Institute on Disability, Independent Living, and Rehabilitation Research

Project 2:
Competencies for a Skilled HCBS Workforce

- **Research Question 1:** What are best practices in providing quality HCBS from literature and research?

- **Research Question 2**: What specific service skills are needed to provide quality home and community-based services based on lived experience?

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Methods

Systematic Review

- Scanned the Peer-Reviewed Literature
- Included 43 articles
- Inclusion criteria:
  - Best practices
  - Competencies
  - Other HCBS/LTSS practices
  - Among people with disabilities

Grey Literature Review

- Scanned Policy & Practice Literature
- Included 26 articles
- Example sources:
  - Government papers
  - Program evaluations, training
  - Programs/guides
  - Policy/issue briefs
  - Resource guides

Key Informant Interviews

- Interviewed people who use or provide HCBS
- Included 49 interviews
  - 22 HCBS users
  - 27 HCBS providers
- HCBS provider interviews included:
  - State waiver personnel
  - Training coordinators
  - Direct service providers

NCAPPS

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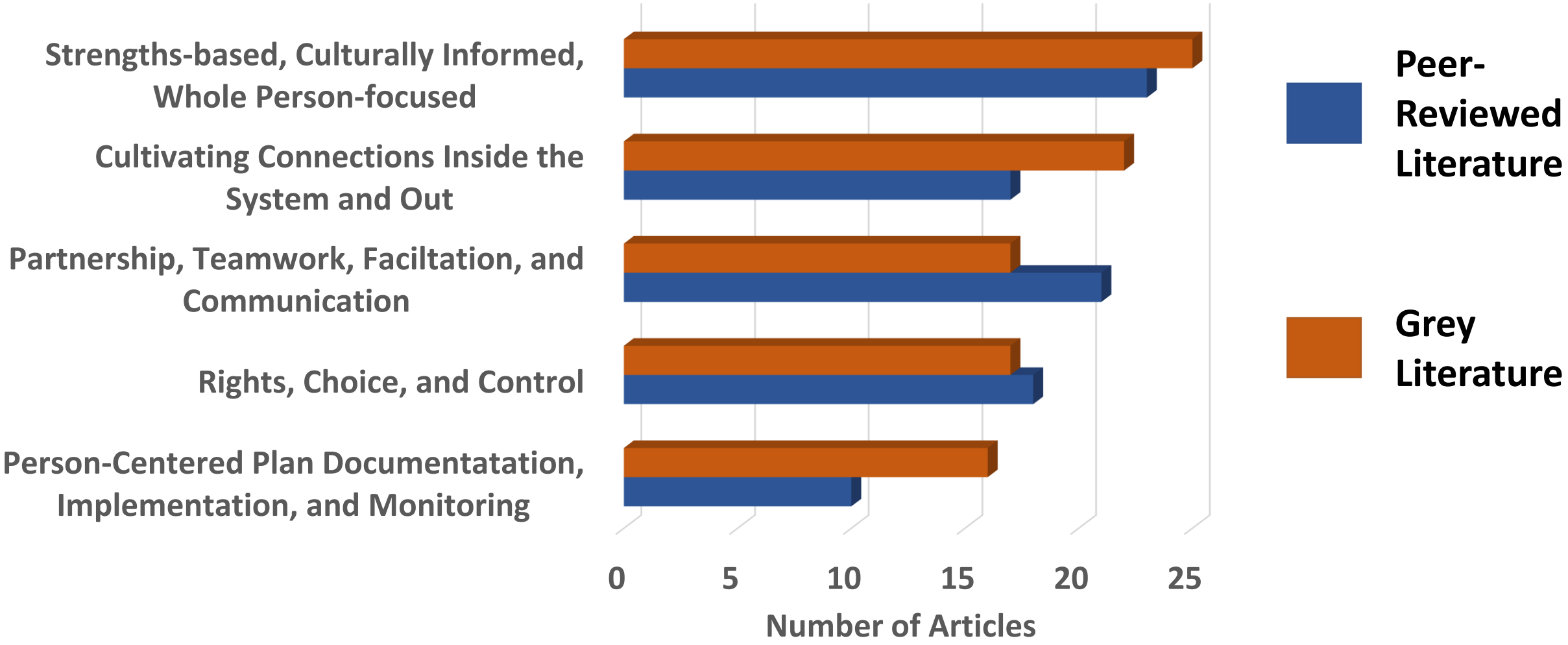
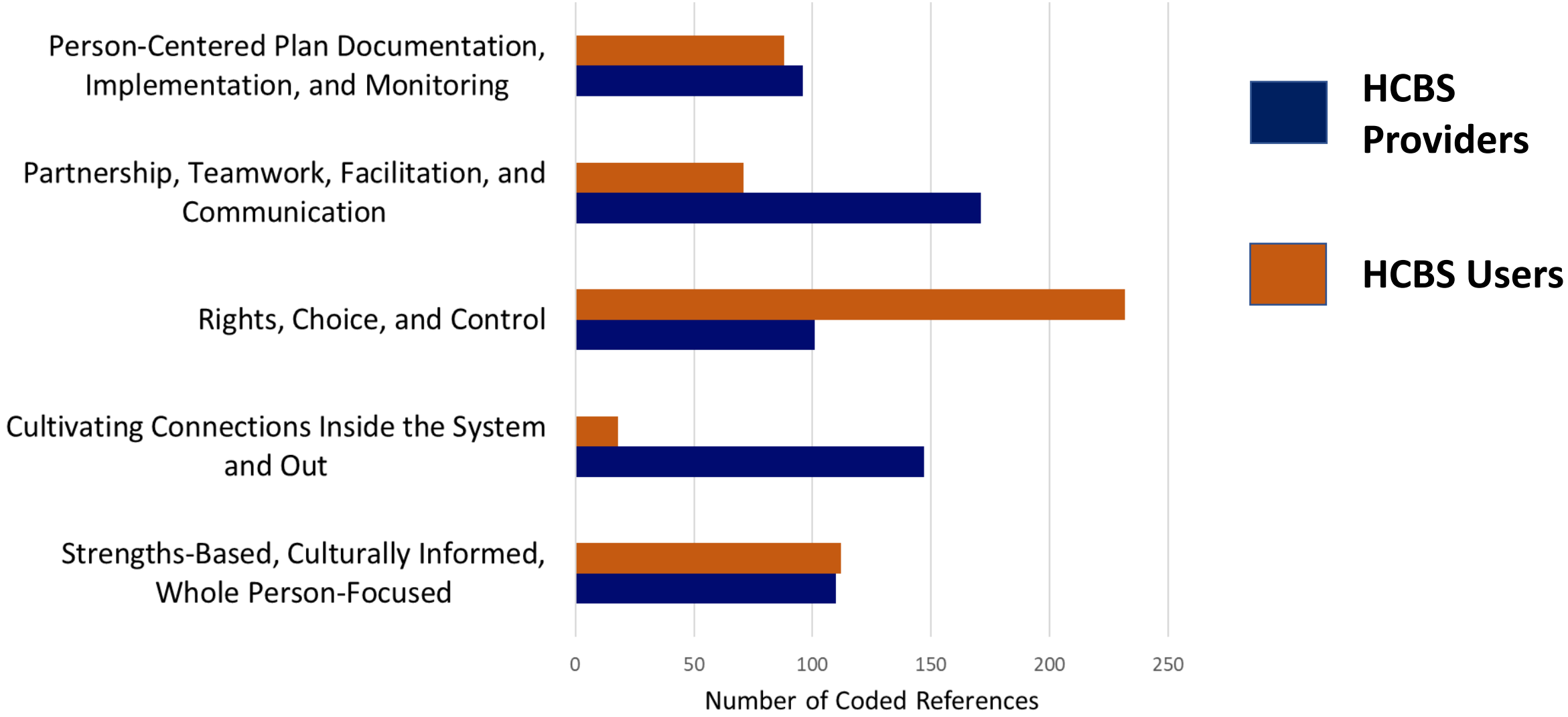
Competencies Identified in Literature



* Numbers add to more than 71 articles because some articles covered multiple themes

Competencies Identified in Interviews



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Strengths-Based, Culturally Informed, Whole Person-Focused: User Perspective

"I have my… queer identity and my family, … the staff that I mentioned … was very supportive. She was a very strong lesbian woman who was very empowering. It was because she would share that part of her experience [of being queer] with me… She came in very humbly into my home. She really respected where she was coming in… She really listened to what I was saying, especially [to] some of experiences that I had had." (User)

Competencies for HCBS Direct Service Providers

- Identify the person's physical, psychological, and social resources
- Learn how biases and implicit stereotypes affect the planning process
- Understand the person's cultural background and identities
- Empower the person in developing self-advocacy, communication, and life skills
- Identify the person's assets and needs during the planning process

Strengths-Based, Culturally Informed, Whole Person-Focused

"What are their risks but what are their [strengths]? So [the HCBS user] ha[s] a very strong family bond. [The HCBS user] ha[s] finished their degree or, you know, just whatever those strengths might be. But also we call them protective factors." (State Department of Services Employee)

Key:
Systematic Review
Grey Literature Review
Key Informant Interviews
Multiple sources

Competencies for HCBS Provider Organizations

- Provide culturally and linguistically specific peer-support services
- **Match users with DSPs with similar life experiences/ cultural backgrounds**
- Offer family intake if desired by the person
- Contract cultural/ethnic organizations to supplement training

Key:
Systematic Review
Grey Literature Review
Key Informant Interviews
Multiple sources

NCAPPS, 2020

NCAPPS

National Center on Advancing Person-Centered Practices and Systems

Key:
Systematic Review
Grey Literature Review
Key Informant Interviews
Multiple sources

Competencies for HCBS Direct Service Providers

- Identify family, friends, and community members to support the person
- Gain a working knowledge of community-based resources
- Asset-based community development and community mapping
- Build mutually beneficial relationships with other disability organizations

"…Asset-based community development is super important … Say [an HCBS user] is really in need of working on a budget. **We have somebody from the local bank that is really happy to sit down and really go step by step. They gain strength through that because they feel empowered"** (Provider)

Community Mental Health for Central Michigan, 2016; National Quality Forum, 2020

Competencies for HCBS Provider Organizations

- Supplement services with coaching programs
- Supplement services with community resources
- Communication channels between self-advocacy networks and provider agencies

Key:

Systematic Review

Grey Literature Review

Key Informant Interviews

Multiple sources

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Rights, Choice, and Control: User Perspectives

"[Our system doesn't] do a good job of providing **meaningful choice** to the Individuals that we support. What we do as a system is, we will slide a piece of paper across to an individual. And that says, 'I was provided the choice of this particular service versus this service.' We don't really talk about... **We don't have dignity of risk conversations**." (User)

"**I just feel like I don't really have a say.** …I was going in the hospital on Monday. I wanted more hours for my aides and they said no." (User)

"Some [direct service providers] have been friendships, but they don't have an issue with me telling them what to do. Does not stand in the way **when they're on the clock, they're on the clock.**" (User)

"Oftentimes things can get delayed or I don't have immediate access to do something that I want to ...**the biggest commodity for a person with a disability**, …**it was time**... Having to wait for things to get done is a big thing." (User)

Competencies for HCBS Direct Service Providers

- Support participants to make decisions about daily routines and personal risks
- Understand and respect individuals' communication styles and preferences
- Know information and laws relevant to LGBT participants
- Ensure that the person has choice over who attends their planning meetings

"Let [the HCBS user] choose who they want us to interview, or who they want part of their meeting and their process, the process of developing a person-centered plan. **There could be 20 people in the room, and that's their choice**. That's all the people that they want." (HCBS Direct Service Provider)

Key:
Systematic Review
Grey Literature Review
Key Informant Interviews
Multiple sources

Davila, 2020; Resources for Integrated Care, 2019; National Resource Center on LGBT Aging, 2020

Competencies for HCBS Provider Organizations

- Offer multiple methods for individuals to provide feedback
- Provide participants training in self-advocacy, civil rights, and facilitation
- Train all levels of staff on client rights
- Provide avenues for clients to choose services and service providers

Key:
Systematic Review
Grey Literature Review
Key Informant Interviews
Multiple sources

CMS, 2020; NQF, 2020; National Resource Center on LGBT Aging, 2020

NCAPPS

National Center on Advancing Person-Centered Practices and Systems

Partnership, Teamwork, Communication, and Facilitation: User Perspective

"Some examples of caregivers that have done a really good job [includes]… just being on time, and reliable, and communicative. If [caregivers are] running late, letting me know that they're going to be 10 minutes late... That gives me a lot of like peace of mind... Communicating with me on the way that I want things done [with movement or cleaning supplies]. **Making sure to ask me what I want rather than just assuming and taking over.**" (User)

Competencies for HCBS Direct Service Providers

- Provide emotional support to family caregivers
- Ensure that the planning process occurs at the times and locations that are convenient to the person and their supporters
- Allocate time to identify specific actions for barriers the person may encounter
- Discuss and document conflict resolution procedures with the person and their supporters
- Center the person's rights and preferences when there are differences of opinion

Key:
Systematic Review
Grey Literature Review
Key Informant Interviews
Multiple sources

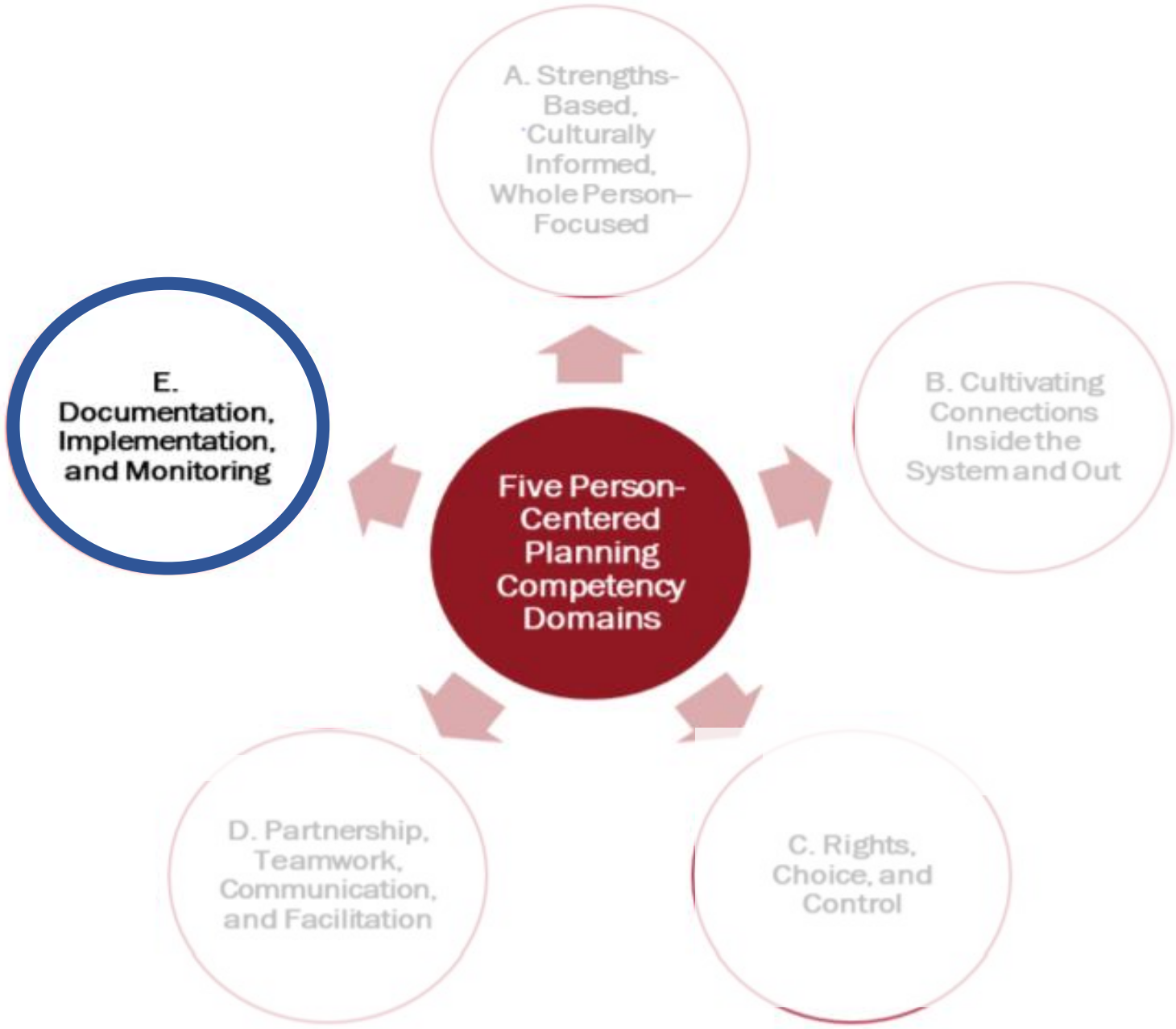
Shaw et. Al (2021); Administration of Community Living, 2014; Minnesota Department of Human Services, 2017; Administration of Community Living, 2014

Competencies for HCBS Provider Organizations

- Provide language supports to the person's supporters
- Provide auxiliary aids and other services to facilitate communication
- Hire peer support professionals and self-advocates

Key:
Systematic Review
Grey Literature Review
Key Informant Interviews
Multiple sources

Administration of Community Living, 2014



NCAPPS

National Center on Advancing Person-Centered Practices and Systems

Documentation, Implementation, and Monitoring: User Perspective

"Before, [the agency] wouldn't even give you your service plan without you asking for it... I have a good case coordinator… and I have a good office manager who has a degree in social work... He's great. [I] don't even have to appeal if I go through him most of the time... **He really gets it."**
(HCBS User)

Key:
Systematic Review
Grey Literature Review
Key Informant Interviews
Multiple sources

Competencies for HCBS Direct Service Providers

- Use an interview guide to discover what is important to participants
- **Ensure that the plan identifies the services and supports the participant will receive and who is responsible for providing them**
- **Integrate direct quotes from the person into their plan**
- Write the plan in plain language

Danilovich et al., 2020; Wisconsin Department of Health Services, 2021; Orlowski & Carter, 2015; Minnesota Department of Human Services, 2017

Competencies for HCBS Provider Organizations

- **Solicit feedback from clients and support persons**
- Budget resources to consistently measure outcomes
- Incentivize more frequent planning meetings
- Ensure avenues for participants to report issues

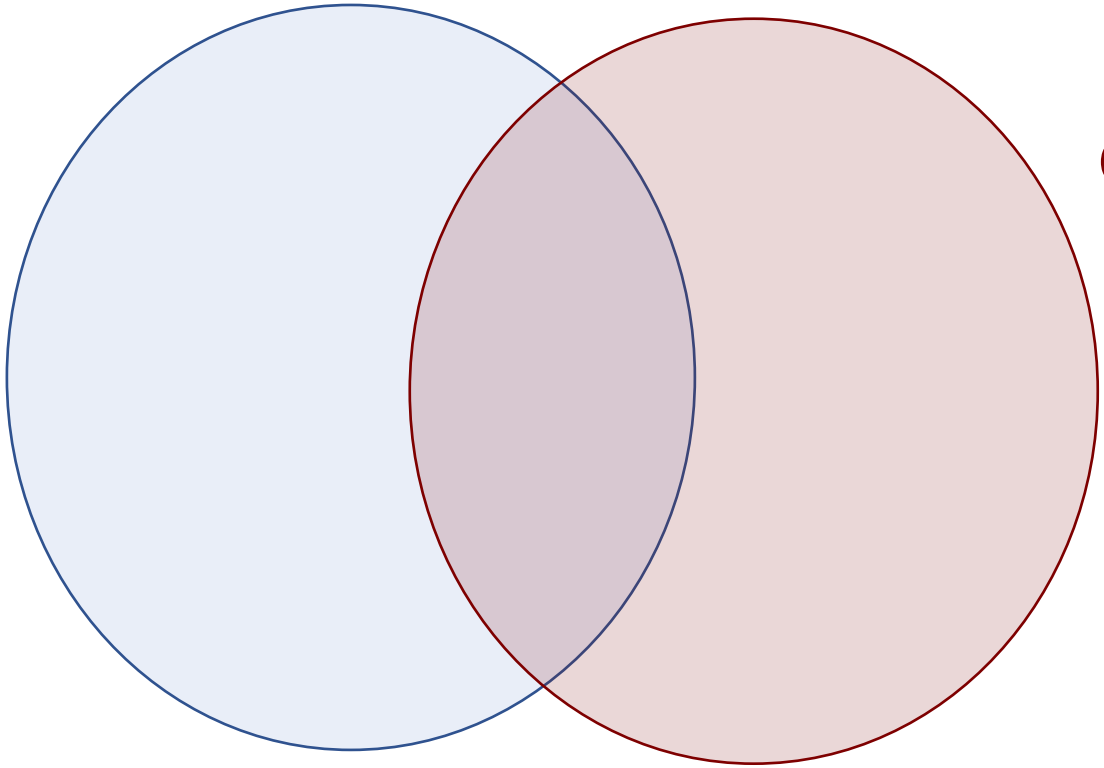
"[When a client has a problem], if it can be fixed, I'm going to go back to the client and see if they want to try to work it out with [the agency]. If not, ultimately**, it's the client's choice**. Our providers are all told that right from the beginning. **Clients can change their mind at any point, just like our providers.**" (Waiver program employee)

Key:
Systematic Review
Grey Literature Review
Key Informant Interviews
Multiple sources

Wisconsin PCP Audit; A Right to Person-Centered Planning; Inclusive Services for LGBT Older Adults; U.S. Administration on Aging, 2010

Other Skills and Competencies

- Systematic Review
  - Professionalism
  - General aging knowledge
  - Financial support
  - Safety
  - Assistive technology



Grey Literature Review
- Health and safety
- Crisis-intervention

Highlighted in Both:
- **Trauma-informed practices**

Barriers to Competencies

- Lack of training, time, resources (workload) and support
- Informational exchange barriers
- Varied state training requirements
- Poor continuity in records
- Deficient trauma-informed framework (training, resources, and supports)
- Measurement and monitoring of person-centered outcomes

Facilitators to Competencies

- Focus on individual preference
- Standardized administrative frameworks and training
- Staff incentivized competency skill and attainment
- Certification programs for career mobility
- Training:
  - Soft skills: empathy, motivational interviewing
  - Impacts of historical trauma experienced by Native people
- National workforce data collection system

Implications & Next Steps

- Training & Supports for Staff
- Trauma-Informed
- Resources & Workforce Crisis
- Outcome Measurement

Other Work by Shirley Ryan AbilityLab Supporting Person-Centered Outcomes in HCBS

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Center for Rehabilitation
Outcomes Research

Competencies in Person-Centered Planning (PCP): Case Studies

- Highlight organizations that are delivering PCP well
- Goal: Provide examples of organizations that do an exemplary job of PCP, the challenges they encountered, and how they succeeded
- **Nominations needed**
  - **Give us your feedback via Zoom chat or email** ntennety@sralab.org

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Competencies in Person-Centered Planning (PCP)

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Training on PCP:

- Developing training
  - Combines PCP with Motivational Interviewing
  - Working with Support Development Associates
  - Include positions at all levels of the organization
  - In the development stage
  - Provide training to organizations to gain feedback for improvement (next spring)

Measurement of Person-Centered Outcomes

- Developing measures of outcomes for individuals
- Identified and defined 9 measure concepts using guidance from participant council
- **Currently**:
  - Cognitive Interviews – testing the clarity of our questions
- **Next Step:**
  - Validity & Reliability of measures
  - Will be looking for provider organizations to collect data (as early as this fall)

CONCEPTS:

Choice and Control Over Diet & Nutrition

Choice and Control Over Finances/Money

Choice and Control Over Healthcare

Choice and Control Over How Time is Spent

Choice and Control Over Living Arrangement

Choice and Control Over Meaningful Relationships

Choice and Control Over Personal Expression

Community Engagement

Dignity of Risk

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Thank you! Questions?

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Check Chat for link to the nomination form for organizations that do Person-Centered Planning well.

Please contact Bridgette Schram at bschram@sralab.org if would like more information or are interested participating in the study