

Understanding and Addressing Unmet Needs in HCBS Through the Lens of Person-Centered Practices

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Welcome to Today's Webinar



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Thank you for joining us to learn about quality and sufficiency of Home and Community-Based Services (HCBS) and their relationship to key health and community living outcomes.

This webinar series is sponsored by the National Center on Advancing Person-Centered Practices and Systems. 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

- 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 captioned in English and Spanish. To access the Spanish captions, please use this link:
<https://www.streamtext.net/player?event=HSRI-2>
- El seminario de web estará subtulado en vivo en Inglés y Español. Para tener acceso a los subtítulos en Español, utilice este enlace: <https://www.streamtext.net/player?event=HSRI-2>
- This live webinar includes polls and evaluation questions. Please be prepared to interact during polling times.



Feedback and Follow-Up

- After the webinar, you can send follow-up questions and feedback about the webinar to 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. 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



Natalie Chong



Finn Gardiner



E. Jennifer Brown



The relationship between unmet need for home and community-based services and health and community living outcomes

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Study Motivation

- Overview of home and community-based services (HCBS)
- Gaps in our understanding of HCBS quality & sufficiency
 - Data from multiple states and Medicaid programs
 - User-reported information and perspectives
 - Study samples with adults of all ages
 - Relationship to key outcomes



Research Questions

1. What is the prevalence of **unmet need** for HCBS?
2. What is the association between **unmet need** for HCBS and key **health** and **community living** outcomes?

National Core Indicators – Aging & Disabilities (NCI-AD)

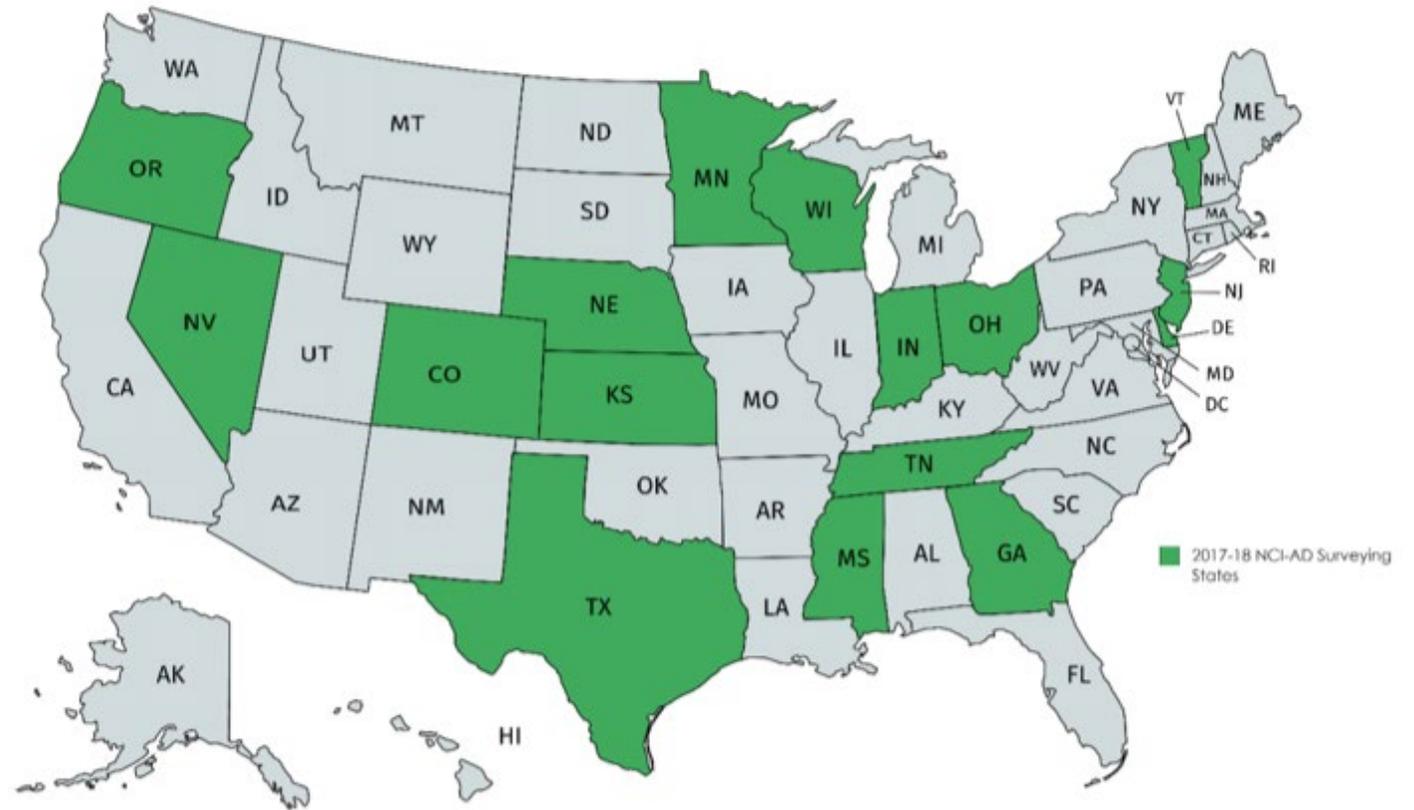
- Target population: Individuals receiving publicly-funded LTSS
- Collects consumer-reported information on quality of services & outcomes annually (>50 indicators)
- Surveys voluntarily fielded by state agencies – each with their own sampling procedures
- In-person interview; allows proxy responses for some items

Overview of NCI-AD Sampling Procedure

1. State agencies volunteer to participate in NCI-AD
2. States select the long-term services and supports (LTSS) programs they want to include in NCI-AD
3. NCI-AD project team advises and tracks each state's program selection and sampling approach
4. States must collect responses from at least 400 individuals
5. States can participate in optional NCI-AD modules

States Participating in NCI-AD (2017-2018)

- Colorado
- Delaware
- Georgia
- Indiana
- Kansas
- Minnesota
- Mississippi
- Nebraska
- Nevada
- New Jersey
- Ohio
- Oregon
- Tennessee
- Texas
- Vermont
- Wisconsin



Our Study Sample

We limited our sample to individuals who:

- Received HCBS through a state Medicaid program
- Lived in the community (i.e., nursing home residents excluded)
- 13 states represented
 - CO, IN, KS, MN, MS, NE, NJ, NV, OR, TN, TX, VT & WI).
 - States were de-identified in the data.
- N = 10,263 respondents

Key Independent Variables

Unmet need for HCBS measured across five domains:

1. Assistance with self-care or other daily activities
2. Services that meet user needs and goals
3. Assistive technology: walker, scooter, wheelchair, hearing aids, glasses, CPAP machine
4. Home modifications: bathroom grab bars, other bathroom modifications, specialized bed, ramp or chairlift, remote monitoring system, emergency response system
5. Transportation to medical appointments and for leisure

Closer Look: Assessing Unmet Need (1 of 2)

Unmet need for assistance, services, & transportation

- Example item: *Do you always get enough assistance with your everyday activities when you need it?*
- If respondents indicate ***no, not always*** or ***sometimes***, they are coded as having unmet need for the corresponding domain.

Closer Look: Assessing Unmet Need (2 of 2)

Unmet need for assistive technology & home modifications

- For each equipment (six under each domain), respondents indicate:
 - **Needs**
 - **Has, but needs upgrade**
 - Has, doesn't need upgrade
 - Does not need
- If respondents indicate **needs** or **has, but needs upgrade** for any type of equipment in each domain, they are coded as having unmet need in that domain.

Outcome Variables

Health Outcomes

- Emergency room visit
- Hospital or rehab stay
- Physical/wellness exam
- Dental exam

Community Living Outcomes

- Active in the community
- Interact with family/friends
- Satisfied with how time is spent during the day
- In control of life

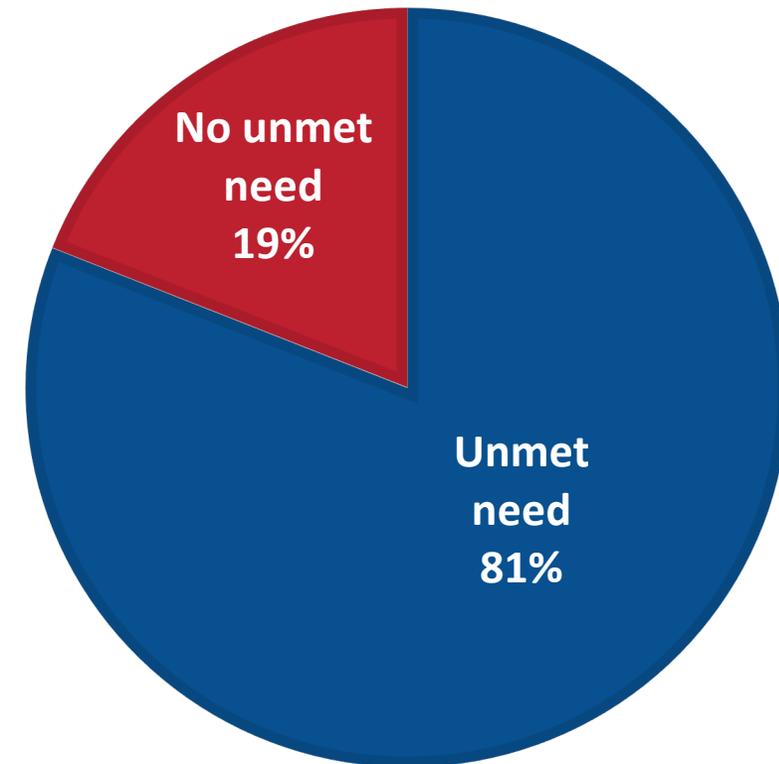
Analysis

- Descriptives
- Multivariate logistic regressions
 - One model per outcome
 - Binary (i.e., yes/no) unmet need and outcome variables
 - Estimated adjusted odds ratios with 95% confidence intervals
- Control variables
 - Demographics: gender, age, race/ethnicity
 - Health & function: needs help with self-care, needs help with other daily activities, self-reported health status
 - Other: residence type, lives alone, rural/urban status

Key Descriptive Findings (1 of 2)

Percent of Respondents with Unmet Need by Domain	
Help with self-care/other daily activities	21.1
Services that meet needs & goals	30.0
Assistive technology	54.3
Home modifications	52.2
Transportation	26.7

PREVALENCE OF UNMET NEED IN AT LEAST ONE DOMAIN



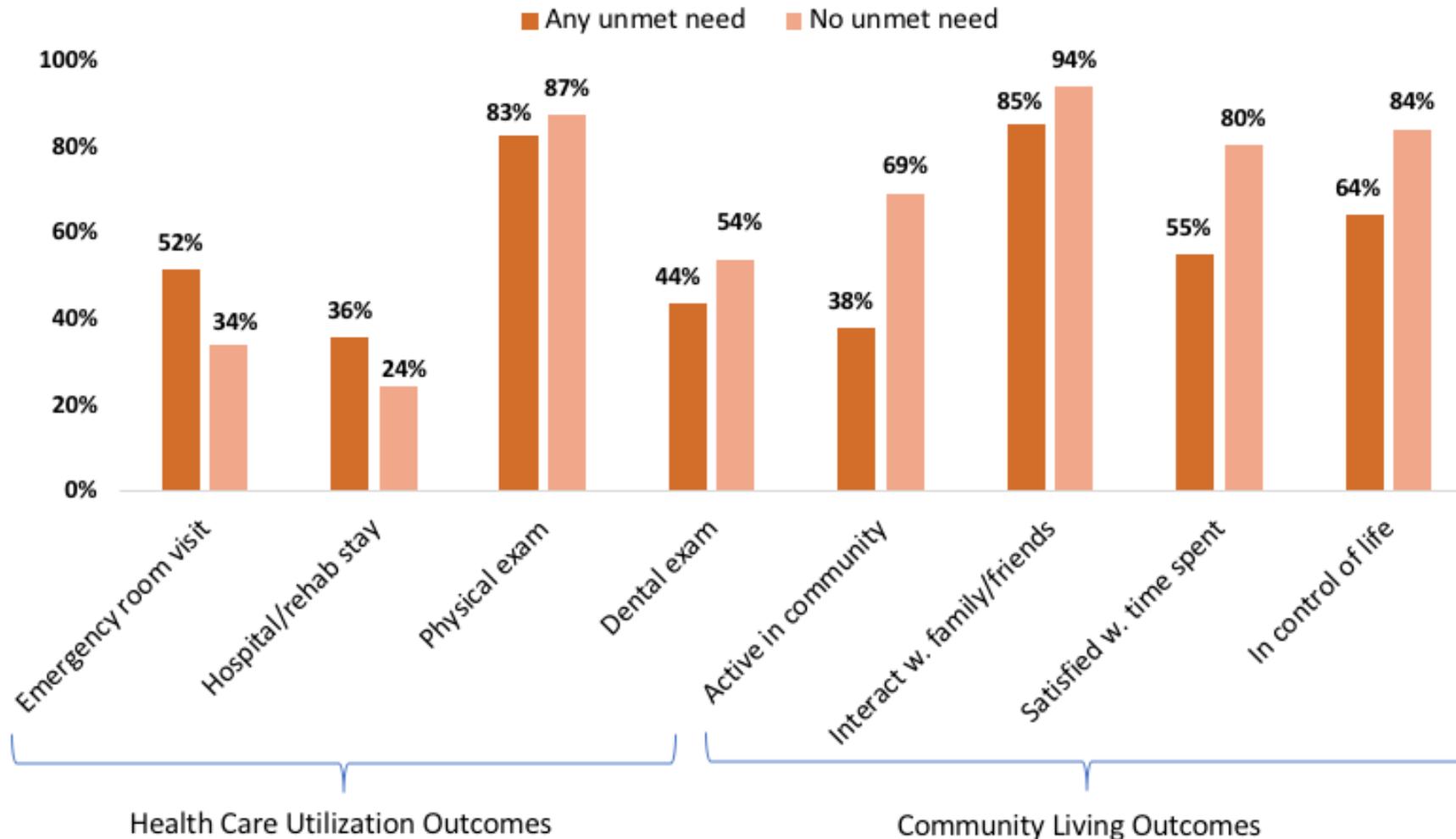
Key Descriptive Findings (2 of 3)

Respondents who had *any unmet need* (vs. no unmet need) were more likely to:

- Be younger in age
- Be non-white
- Live at home/senior living
- Live alone
- Have poor health status

Key Descriptive Findings (3 of 3)

Prevalence of Health Care Utilization & Community Living Outcomes by Unmet Need Status





Key Findings: Multivariate Analysis

Overall, unmet need was associated with:

- Greater likelihood of an ER visit and a hospital/rehab stay
- Reduced likelihood of receiving both types of preventative care (wellness and dental visits)
- Lower likelihood of experiencing all community living outcomes

Key Findings: Unmet Need on Health

Comparing across types of unmet need:

- Unmet need for *assistive technology* was associated with:
 - Greatest likelihood of having an **ER visit** (AOR: 1.60; CI: 1.46–1.77) and a **hospital/rehab stay** (AOR: 1.54; CI: 1.39–1.71)
 - Lowest likelihood of having a **physical exam** (AOR: 0.74; CI: 0.65–0.84)
- Unmet need for *transportation* was associated with the lowest likelihood of having a **dental exam** (AOR: 0.70; CI: 0.63–0.78)

AOR: Adjusted odds ratio; CI: confidence interval

Key Findings: Unmet Need on Community Living

Comparing across types of unmet need:

- Unmet need for *transportation* was associated with the lowest likelihood of:
 - **Being active in the community** (AOR: 0.47; CI: 0.41–0.53)
 - **Interacting with friends/family** (AOR: 0.51; CI: 0.43–0.60)
- Unmet need for *services that fully meet recipient needs and goals* was associated with the lowest likelihood of
 - **Satisfaction around how time is spent** (AOR: 0.46; CI: 0.41–0.52)
 - **Feeling in control of life** (AOR: 0.42; CI: 0.37–0.48)

Study Limitations & Strengths

Limitations

- Non-representative sample of U.S. HCBS population
- Cannot control for cross-state differences and variation between programs
- Cross-sectional design
- Do not know if health care utilization outcomes are preventable

Strengths

- First-look at the NCI-AD data beyond NCI-AD annual reports
- Multi-state picture of experiences of HCBS recipients
- Richness of user-reported data

Finn Gardiner



Unmet Needs – Inherent Conflict

- Conflict
 - Person centered planning is asset based – when done well it is not based on a system or availability of services
 - Home and Community Based Services use a medical model and are deficit based



Unmet Needs – Service System Limits

- Can't get a good life from a service system
 - Natural and generic supports

Navigating Unmet Needs in New Jersey (NJ)

- System is difficult to learn and understand how to get needs met
 - Multiple service systems
 - Manual 230 pages
 - Budgets may be large but money is siloed
 - Dependent on strong natural supports – savvy in the system

Unmet Needs – Lack of Enforcement (NJ)

- When a requested service is denied
 - Appeals are stacked against the person
 - Up against Assistant Attorney General
 - Takes a long time
 - No ruling – just recommendation

Some Good News – Advocacy and Education (NJ)

- Ombudsman
 - <https://www.disabilityombudsman.nj.gov/treasury/njombudsman/>
- New office on self direction and education
 - People with disabilities and family members playing key role
 - <https://nj.gov/humanservices/ddd/individuals/community/education/>
- Commitment to infusing person centered planning across the service system
 - <https://www.lifecoursetools.com/>

Some Good News – All Get Some (NJ)

- All people get some services
 - 2 waiver programs for
 - Waitlist for Community Care Program – which has residential component

Some Good News – Shift in Culture (NJ)

- Transparency
 - Access to decision makers within the system
 - Seat at the table
- Access to housing subsidies
- Support Brokerage
 - Designed to help people find self directed services & supports



Questions?

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

Real-Time Evaluation Questions (cont.)

- 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.

Register for upcoming webinars at
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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) .





Supplemental Material

HCBS Program Names and Sample Sizes by State (1 of 2)

State	HCBS Program	Sample Size
Colorado	<ul style="list-style-type: none">• Elderly, Blind, and Disabled (EBD) Waiver• Colorado Choice Transitions (CCT)	806
Indiana	<ul style="list-style-type: none">• Aged and Disabled Waiver (A&D)• Traumatic Brain Injury (TBI) Waiver	362
Kansas	<ul style="list-style-type: none">• Frail and Elderly (FE) Waiver• Physical Disability (PD) Waiver• Traumatic Brain Injury (TBI) Waiver	207
Minnesota	<ul style="list-style-type: none">• Elderly Waiver (EW)• State Plan Funded Home Care• Community Alternative Care (CAC) Waiver• Community Access for Disability Inclusion (CADI) Waiver• Brain Injury (BI) Waiver	2,717
Mississippi	<ul style="list-style-type: none">• Assisted Living (AL) Waiver• Elderly and Disabled (ED) Waiver• Independent Living (IL) Waiver• Traumatic Brain Injury/Spinal Cord Injury (TBI/SCI) Waiver	428

HCBS Program Names and Sample Sizes by State (2 of 2)

State	HCBS Program	Sample Size
Nebraska	<ul style="list-style-type: none"> • Aged and Disabled (A&D) Waiver • Traumatic Brain Injury (TBI) Waiver • Personal Assistance Services (PAS) 	367
New Jersey	<ul style="list-style-type: none"> • MTLSS Home and Community-Based Services 	606
Nevada	<ul style="list-style-type: none"> • Home and Community Based Waiver for the Frail Elderly • Home and Community Based Waiver for Persons with Physical Disabilities 	388
Oregon	<ul style="list-style-type: none"> • Community First Choice (CFC), Home and Community-Based Services 	424
Tennessee	<ul style="list-style-type: none"> • TennCare Choices, Home and Community-Based Services 	511
Texas	<ul style="list-style-type: none"> • STAR+PLUS Home and Community-Based Services 	1,485
Vermont	<ul style="list-style-type: none"> • Choices for Care • Traumatic Brain Injury (TBI) Program 	428
Wisconsin	<ul style="list-style-type: none"> • Family Care Program • Family Care Partnership Program • IRIS (Include, Respect, I-Self Direct) Program 	1,765
		Total = 10,494