ILLINOIS DEPARTMENT OF
Healthcare and
Family Services

JB Pritzker, Governor
Theresa Eagleson, Director

201 South Grand Ave. East
Springfield, Illinois 62704

Telephone: 1-217-782-1200
TTY: (800) 526-5812

MEETING NOTICE

Medicaid Advisory Committee

Community Integration Subcommittee Meeting

Thursday, January 6, 2022, 3-5 PM

Due to COVID-19 concerns, this meeting will be held using WebEx:

- Join from the meeting link:
  https://illinois.webex.com/illinois/j.php?MTID=m72f09b0f5279fe1dd0c1be9a935bc38c

- Join by phone:
  +1-312-535-8110 United States Toll (Chicago)
  +1-415-655-0002 US Toll
  Meeting number (access code): 2462 414 2109

HFS is committed to ensuring that this session meets the disability access needs of all participants. Please contact Gabriela Moroney at 217-843-1415 or Gabriela.M.Moroney@illinois.gov with any disability access requests as early as possible.

WebEx tips:

- You may use your computer's audio or the phone option for sound; in our experience the "Call-me" option has the best sound quality.
- If you are calling-in and not using the WebEx link, please send an email Gabriela.M.Moroney@illinois.gov with *MAC CI Attendee* in the Subject line to provide name and organization for meeting minutes.

Agenda

I. Call to Order
II. Review and approval of meeting minutes from November 4, 2021
III. Public comment
IV. Update on PUNS list
V. Presentation on HCBS Settings Rule
VI. Presentation on Program of All-Inclusive Care for the Elderly (PACE).
VII. Discussion
VIII. Identify agenda focus for March meeting
IX. Adjourn

Public Comment

The MAC Community Integration Subcommittee is seeking comment from members of the public. On January 6, 2022, the subcommittee is especially interested in hearing about the opportunities and unmet needs for improving community integration for older adults and individuals with disabilities.

If you wish to offer comment during the meeting, please submit an email request with the statement *MAC CI Public Comment* in the Subject line. Send this request to Gabriela.M.Moroney@illinois.gov no later than 5 PM on January 4, 2022. The Department will try to accommodate as many requests as possible, however there is limited availability for public comments. At the Department's discretion and based upon the public comment time allotted, each speaker will be limited to 1-3 minutes.

Written comments are welcome and should be submitted to the same email address by 5 PM on January 4, 2022. Please include *MAC CI Written Comment* in the Subject line.

Specific questions the subcommittee is interested in are:

- Which groups of Medicaid enrollees are not fully served by Illinois Medicaid-funded home and community-based services? What barriers are they experiencing?
- Where and with which populations is demand for home and community-based services rising?
- Do delays exist in accessing Medicaid HCBS services? If so, which services are affected and what is your understanding of the nature of the delays?
- What are some ideas for expanding access to Illinois Medicaid home and community-based services?

ILLINOIS DEPARTMENT OF
Healthcare and
Family Services

JB Pritzker, Governor
Theresa Eagleson, Director

201 South Grand Ave. East
Springfield, Illinois 62704

Telephone: 1-217-782-1200
TTY: (800) 526-5812

Medicaid Advisory Committee
Community Integration (CI) Subcommittee
WebEx Meeting DRAFT Minutes
November 4, 2021, 3-5 PM

CI Subcommittee Members Present

Amber Smock (Chair), Access Living
Jessie Beebe, AIDS Foundation of Chicago
Kathy Carmody, Institute on Public Policy for People with Disabilities
Sydney Edmond, Illinois Public Health Institute
Maria ‘Carmen’ Gonzalez DJangi, Metropolitan Family Services
Lori Hendren, AARP
LaShun James, Addus Homecare
Jordyn Jensen, UIC Department of Disability and Human Development
Ann Lundy, Access Community Health Network
Jodi Mahoney, North Central Behavioral Health Systems
Missy Munday, Cornerstone Services
Marsha Nelson, Shawnee Health Service
Mark Stutrud, Lutheran Social Services of Illinois
Ashley Warren, NAMI Chicago
Greg Will, SEIU Healthcare Illinois-Indiana

Department of Healthcare and Family Services (HFS) Staff Present

Melishia Bansa
Arvind Goyal, MD
Maureen Haugh Stover
Kiran Mehta
Robin Morgan
Gabriela Moroney
Lauren Tomko

Other State Staff Present

Amy Lulich, Department on Aging (Aging)
Carrie Wilcox, Department of Human Services (DHS) Division of Mental Health
Farrah Borders, Aging
Joe Danner, Aging
Kimberly Mercer-Schleider, Illinois Council on Developmental Disabilities
Lora McCurdy, Aging
Rahnee Patrick, Director, DHS Division of Rehabilitation Services
Sally Lisnek, Aging
Sarah Myerscough-Mueller, DHS Division of Developmental Disabilities

Public Attendees

Paul Bennett, AgeOptions
Kathy Chan, Cook County Health
Sara Dado, Lightways
Josh Evans, Illinois Association of Rehabilitation Facilities (IARF)
Kristen Feld, Clearbrook
Brenda Fleming, West Central Illinois Area Agency on Aging
Leticia Galvez, CareAdvisors
Val Guzman, Age Guide Northeastern Illinois
Kristina Hamilton, American Lung Association
Jill Hayden, Medicaid Policy Network
Dave Hurter, Amita Health
Martha Jarmuz, Choices Coordinated Care Solutions
Marsha Johnson, CCSI-Case Coordination
Andrea Kindseth- LIFE CIL
Winnie Lam, Chinese American Service League
Kelsie Landers, Heartland Alliance
Jana Le, Vietnamese Association of Illinois
Emily Miller, IARF
Shqipe Osmani, SO Strategies LLP
Brielle Osting, CareAdvisors
Beth Owens, IARF
Shelly Richardson, Statewide Independent Living Council of Illinois
Andrea Rizor, Equip for Equality
Trisha Rodriguez, Illinois Association of Medicaid Health Plans
Meryl Sosa, Illinois Psychiatric Society
Darrell Stoller, Apostolic Christian Life Points
Martha Tellez, Medical Home Network
Katie Thiede, AllianceChicago
Ryan Voyles, Health News Illinois
Kaoru Watanabe, Cambodian Association of Illinois

I. **Call to Order** – Amber Smock, chairperson of the subcommittee, called the meeting to order at 3:04 PM.

II. **Review and approval of meeting minutes from September 2, 2021**—Ann Lundy moved to approve the minutes from September 2nd, 2021. Kathy Carmody seconded the motion, which was approved by the subcommittee.

III. **Discussion of HFS mandatory training for subcommittee members** – Kiran Mehta from HFS reviewed the mandatory training requirements for subcommittee members. All subcommittee members will receive a login to the OneNet system to complete the required trainings.

IV. **Department of Human Services - Division of Rehabilitation Services brief presentation on customer feedback on Home Services Program** – Director Rahnee Patrick presented on a Town Hall process used to gather customer feedback on the Home Services Program. Some questions and answers were offered. See Appendix A for presentation.

V. **Input from subcommittee members on needs and opportunities for improving community integration for older adults and individuals with disabilities** – Subcommittee members shared observations and concerns about the needs of older adults and individuals with disabilities to remain integrated in the community. Several key themes emerged:

Services

- The service array for individuals with a primary diagnosis of Substance Use Disorder may not be sufficient to prevent institutionalization.
- Varying requirements and services from one home- and community-based services (HCBS) waiver to the next make navigation challenging.
- Provider staff retention issues affect service availability.
- No HCBS waiver services for persons with mental illness.

Administrative processes

- Billing requirements can be onerous for providers, such as a requirement to bill Medicare and receive a denial before billing Medicaid, when it is already established that Medicare will deny the claim.
- Restriction on same-day billing for similar services can limit care provided.
- The multiple communications and paperwork that many customers receive can be confusing. There is a need to simplify the interface for customers.

Stakeholder awareness

- Lack of knowledge of the important opportunity to transition individuals newly admitted to nursing facilities back to the community with home and community-based services. Lack of awareness among housing providers of waiver services and how to access them.
- Need for marketing and outreach to increase customer knowledge and public awareness.

Accessing services

- The outreach and referral process for HCBS is not accessible for the population served by housing providers.
- The digital divide makes accessing services difficult. For example, no internet, inability to use laptop, electronic systems that are difficult to navigate. This is especially true for older adults and persons experiencing homelessness.
- Waiting lists are a big obstacle for accessing developmental disabilities waivers (referring to the PUNS list).
- Assessments for waiver enrollment can take from 30 days (Aging) to 60 days (HSP).

Planning

- Need for systematic shift to using predictive health measures to make decisions, rather than always being reactive.
- Will four-person group homes for persons with intellectual or developmental disabilities be considered institutional settings in the future.

Ideas for expanding access to HCBS

- Make the customer interface/entry point more accessible. For example, provide clear training or video for those working directly with customers to create awareness of HCBS programs and a simple way to access them.
- Work with faith-based community organizations.
- Simplify messaging.
- Promote better quality of life.
- Innovative models such as PACE.
- Create a new method of access that puts individuals at the center.
- Address language barriers.
- Ensure that care coordination models do not rely exclusively on technology such as phones, email, and/or texting.
- Ensure good customer service.

VI. **Public comment**

Shelly Richardson spoke to the subcommittee about her experience providing and advocating for providers of home-based services. Ms. Richardson expressed her hope that Medicaid will develop a Bridge subsidy for housing. She noted that waitlists are long, and that there would be value in expediting the approval of home modifications quickly. She noted that wages for in-home workers are not enough for the grueling nature of the work. She advocated for more telehealth and expressed concern about the disparity between hours approved for a person under 60 versus a person over 60.

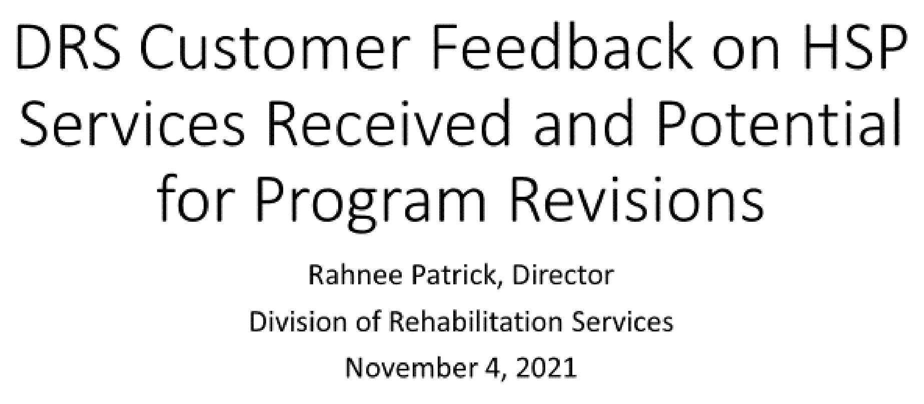
Written public comment was submitted by the Illinois Hospice & Palliative Care Organization and is included as Appendix B.

VIII. **Discussion** – At various points throughout the meeting, members of the public jumped in with their comments. Josh Evans asserted lack of a support system for adolescents with autism or ID/DD experiencing crisis or high support needs. Andrea Kindseth stated that individuals over 60 with higher need are limited in the in-home services they can receive due to service cost maximum on home services accessed through the Aging waiver.

IX. **Identify agenda focus for November meeting** – Three topics were identified:
Public Comment on needs and opportunities for improving community integration for older adults and individuals with disabilities;
Update on the PUNS list;
Presentation on HCBS Settings Rule; and
Presentation on Program of All-Inclusive Care for the Elderly (PACE).

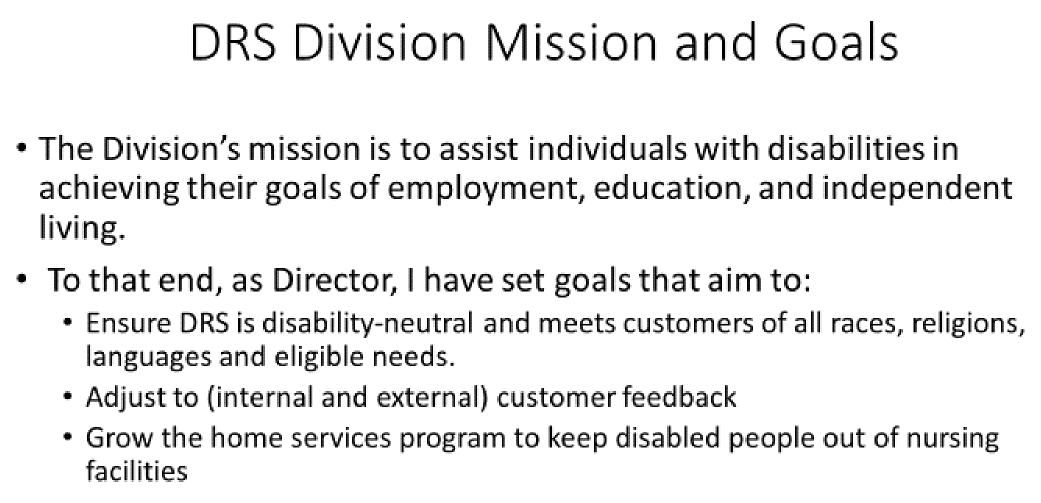
IX. **Adjourn** – The meeting was adjourned at 5 PM.

Appendix A



DRS Customer Feedback on HSP Services Received and Potential for Program Revisions

Rahnee Patrick, Director
Division of Rehabilitation Services
November 4, 2021



DRS Division Mission and Goals

- The Division’s mission is to assist individuals with disabilities in achieving their goals of employment, education, and independent living.
- To that end, as Director, I have set goals that aim to:
  - Ensure DRS is disability-neutral and meets customers of all races, religions, languages and eligible needs.
  - Adjust to (internal and external) customer feedback
  - Grow the home services program to keep disabled people out of nursing facilities

HSP Response to the Pandemic

- Appendix K: Flexibilities in policy during the Covid-19 Pandemic
  - Spouses and Parents as providers
  - Increased Respite hours
  - Expanded service delivery by caregivers while Customer is hospitalized
  - Telephonic assessments
  - Home Delivered Meals: delivery of fresh, frozen and shelf-stable foods
- Timesheets: All field offices now have a drop box or mail slot for submission of timesheets. A printable timesheet is also available
- PPE: Customers may contact their local offices for PPE, including gloves and masks.
- Statewide DRS Hotline: 1-877-581-3690
- For further information on HSP's response to the pandemic, please visit https://tinyurl.com/hspcovid.

Obtaining Customer Feedback

- To ensure the Division is attuned to the experience of its customers, we have held several town halls across the State for HSP Customers, to speak directly to them about recent changes in program policy and projects implemented, as well as to hear their feedback and develop contacts to correct any issues.
- DRS has also launched a Customer Satisfaction Survey

HSP Town Hall Meetings—Common Issues/Questions Raised (Cont.)

- Questions asked about:
- Does the customer need to be there when PA is signing packets?
- How are we addressing PA shortages?
- If a month has less than 31 days may we use all our hours for the month or just so many in a day?
- Is the IP allowed to drive? Do you get paid for driving?
  - Per the IL488-2252 Individual Provider Payment Policies Form, It is strictly prohibited to transport a customer in the Individual Provider's automobile or other mode of transport while performing any duty as an Individual Provider.
- Can PA helping with mowing, weed eating, yard work, etc?
- Customer is making PA do cleaning/heavy lifting daily, should that be a part of duties?

Responses to Customer Feedback at Town Halls (cont.)

- Review of eligibility criteria for HSP services
  - Considering adjusting asset limit, which resources are exempt from consideration when determining eligibility
- Exploring addition of services to the Program
  - Review of policy on transportation of customers
- Clarification of service limitations
  - What tasks providers can complete for customers/where they can be completed
- Exploring additional methods of submission of program documents/interaction with the program
  - EVV portal, potential mobile application
  - Looking at a one-stop shop online solution for HSP—similar to MyChart, etc, would have the ability to fill out most program forms and submit online, and communicate directly with local office staff through the system.

Appendix B

Written Testimony from the Illinois Hospice & Palliative Care Organization to the Illinois Medicaid Advisory Committee's Community Integration Subcommittee

Thursday, November 4th, 2021, 3:00-5:00 PM

On behalf of the Illinois Hospice & Palliative Care Organization (IL-HPCO) and our provider members that care for 45% of Medicare hospice patients served in IL in 2020, we offer testimony about the population of Medicaid enrollees experiencing a serious illness or advanced frailty. Sometimes, these individuals are also served by Medicare as dual-eligible, but not always. Often, this is the population that can or do benefit most from Illinois Medicaid-funded home and community-based services.

Thanks to modern medicine, Illinoisans diagnosed with metastatic cancer, Alzheimer's disease, congestive heart failure, renal failure, ALS, advanced frailty, or another serious illness can expect to live longer even with these complex conditions. However, today's fragmented health care system often makes it difficult for them to stay out of the hospital and puts a burden on the people closest to them.

Far too often, an individual's quality of life, personal goals and long-held values and beliefs sit on the sidelines of their medical care. Data from 2016, compiled by the Coalition to Transform Advanced Care, show that Illinois citizens facing a serious illness have high Medicare spending, long hospital and ICU stays, high numbers of preventable hospitalizations for seniors, high patient co-pays and late hospice admissions when compared with other states. These shortcomings raise the vulnerability and fragility of people with serious illness and their primary caregivers.

Community-based palliative care is an evidence-based solution to these problems. Palliative care is specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a specially trained team of doctors, advanced practice nurses, registered nurses, social workers, and others who work together with a patient's existing doctors to provide an extra layer of support. Palliative care is based on the needs of the patient, not on the patient's prognosis. This care is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment.

Community-based palliative care helps address two important barriers for seriously ill people not fully served by Illinois Medicaid-funded home and community-based services.

Barrier 1: Over reliance on the traditional medical model of treating serious illness leaves people cycling in and out of the hospital due to unmet symptom burdens and unaddressed social needs. Patients and caregivers cope from crisis to crisis, too overwhelmed to identify home and community-based services that could improve their quality of life.

A 2010 study entitled *Measuring Families' Perceptions of Care Across a Health Care System*[1], showed that palliative care reduced symptom burden by 66% with improvements lasting months after the initial consultation. Other studies demonstrate that palliative care delivered in the outpatient, skilled nursing and home-based settings reduces avoidable health care spending and utilization by 35% or more, saving Medicare or Medicaid resources while giving patients more days at home.

Barrier 2: Especially for the seriously ill population, Person-Centered Planning that incorporates both medical and social needs is not adequately reimbursed and therefore often fails to effectively match the family's needs and circumstances with available Medicaid-funded services.

Studies consistently show that patients and family caregivers may be unaware of prognosis; that physicians are often inaccurate or reluctant to share detailed prognostic information; and that patients of certain socioeconomic statuses or races may be less aware of their prognosis.[2,3]

Without a realistic understanding about the future, people struggling with serious illness are at risk of physical and psychological suffering at the end of life[4] and may not be aware of the Medicaid home and community-based services that are available to support their needs.

Community-based palliative care providers are highly trained to facilitate open communication with patients and their family members on an ongoing basis, and in particular, social workers are adept at connecting families to services in the community that improve quality of life. Data show that person-centered planning improves care by matching treatment choices with each person's preferences.[5]

Based on its effectiveness in addressing these barriers, we believe incorporating palliative care services into Medicaid and requiring that enrollees in the Medicare-Medicaid Alignment Initiative (MMAI) have access to palliative care would expand access to Illinois Medicaid home and community-based services for people with serious illness and their caregivers.

Thank you for the opportunity to present this testimony highlighting important aspect of care that affect some of our state's most vulnerable Medicaid enrollees.

Respectfully submitted,

Sara Dado, LCSW
Board Chair- Illinois Hospice and Palliative Care Organization
Chair- Serious Illness Workgroup
Senior Director of Clinical Programs- Lightways Hospice and Serious Illness Care
sdado@lightways.org
847-636-0046

Please refer to The Administration for Community Living (ACL) - Principles for Person-directed Services and Supports during Serious Illness for specific information related to living with serious illness according to personal values and goals, person-directed planning and decision-making, palliative care and hospice.[6]

1. Casarett D, Shreve S, Luhrs C, Lorenz K, Smith D, De Sousa M, Richardson D. Measuring families' perceptions of care across a health care system: preliminary experience with the Family Assessment of Treatment at End of Life Short form (FATE-S). J Pain Symptom Manage. 2010 Dec;40(6):801-9. doi: 10.1016/j.jpainsymman.2010.03.019. PMID: 20813493.
2. Bernacki RE, Block SD; American College of Physicians High Value Care Task Force. Communication about serious illness care goals: a review and synthesis of best practices. JAMA Intern Med. 2014 Dec;174(12):1994-2003. doi: 10.1001/jamainternmed.2014.5271. PMID: 25330167.
3. Temel JS, Greer JA, Admane S, Gallagher ER, Jackson VA, Lynch TJ, Lennes IT, Dahlin CM, Pirl WF. Longitudinal perceptions of prognosis and goals of therapy in patients with metastatic non-small-cell lung cancer: results of a randomized study of early palliative care. J Clin Oncol. 2011 Jun 10;29(17):2319-26. doi: 10.1200/JCO.2010.32.4459. Epub 2011 May 9. PMID: 21555700.
4. Committee on Approaching Death: Addressing Key End of Life Issues; Institute of Medicine. Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life. Washington (DC): National Academies Press (US); 2015 Mar 19. PMID: 25927121.
5. Human Services Research Institute. (2019). Person-Centered Thinking, Planning, and Practice: A National Environmental Scan of Definitions and Principles. Cambridge, MA: National Center on Advancing Person-Centered Practices and Systems.
6. https://acl.gov/sites/default/files/Aging%20and%20Disability%20in%20America/Serious%20Illness%20Principles%208-30-17%20508%20compliant.pdf