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, March 3, 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=m501fcfbcdb0c034a53997a64d94d3374

OR

- Join by phone:
  +1-312-535-8110, United States Toll (Chicago)
  +1-415-655-0002, US Toll
  Meeting number (access code): 2458 482 0452

- WebEx tip: 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.

IMPORTANT: 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.

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.

Agenda

I. Call to Order
II. Roll call
III. Review and approval of meeting minutes from January 6, 2022
IV. Public comment
V. Discussion of Illinois's HCBS American Rescue Plan Act (ARPA) spending plan: https://www2.illinois.gov/hfs/SiteCollectionDocuments/11012021IllinoisARPHCBSEnhancedFMAPSpendingPlan.pdf#search=ARPA%20spending%20plan
VI. Discussion of top Illinois HCBS workforce issues
VII. Review proposed agendas for May and July meetings
VIII. Discussion

IX. Adjourn

In addition to the ARPA spending plan noted above, Subcommittee members are invited to review background material on the waiver for Persons with HIV/AIDS.

- Fact sheet contains useful summary: https://www2.illinois.gov/hfs/MedicalClients/HCBS/Pages/hiv.aspx
- Currently active waiver contains rich detail: https://www2.illinois.gov/hfs/SiteCollectionDocuments/CurrentHIVorAIDSWaiver.pdf

Public Comment

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 March 2, 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 March 2, 2022. Please include *MAC CI Written Comment* in the Subject line.

Specific questions the subcommittee is interested in are:

- What are your recommendations for how Medicaid HCBS can be used to better support certain populations?
    - Immigrants, including undocumented persons
    - Persons with HIV/AIDS
    - Persons with disabilities/seniors returning to the community from jail/prison

- What are your recommendations to improve career opportunities in HCBS? What are the best ways to support those currently providing supports without pay?

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Medicaid Advisory Committee
Community Integration (CI) Subcommittee
WebEx Meeting DRAFT Minutes
January 6, 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
- LaShun James, Addus Homecare
- Amie Lulinski, The Arc of Illinois
- 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
- Emily Brigman
- Arvind Goyal, MD
- Lisa Gregory
- Cynthia Mester
- Robin Morgan
- Gabriela Moroney
- Lauren Tomko
- Pamela Winsel

Other State Staff Present

- Mike Berkes, Department on Aging (Aging)
- Meg Cooch, Department of Human Services (DHS) Division of Developmental Disabilities (DDD)
- John Eckert, Aging
- Mariel Hamer-Sinclair, DHS Division of Rehabilitation Services (DRS)
- Sally Lisnek, Aging
- Amy Lulich, Aging
- Lora McCurdy, Aging
- Kimberly Mercer-Schleider, Illinois Council on Developmental Disabilities
- Sarah Myerscough-Mueller, DHS-DDD
- Rahnee Patrick, Director, DHS-DRS
- Allison Stark, Director, DHS-DDD
- Carrie Wilcox, DHS Division of Mental Health

Public Attendees*

- Allan Bergman
- Andrea Kindseth, LIFE CIL
- AndreaR
- Andrew Smith, DBSA he/him
- Angel Bates-Smith
- Anne Gunter
- Barb Cohen
- Becky Ogrodny
- Beth Owens
- Bob Peterson
- Brittani Provost UIC-DSCC
- Bruce Carmona
- Chante Gamby
- cthompson
- Cynthia Mester
- Darryl Robinson
- Dave Hurter
- David Berkey
- Elizabeth Nelson
- Fabian Camarena
- Gilbert Lichstein
- Hershel Jackson
- Jae Jin Pak
- Januario Ortega
- Jenna F. IMPACT
- Jesus Chuy Campuzano
- Jill Hayden
- Joyce Colton
- Juan Flores
- Kaoru Watanabe
- Kathy Weiman
- Kevin Heffernan
- Kira Meskin
- Marina Salman
- Mary Cooley
- Maureen Howard
- Ryan McGraw
- Ryan Voyles
- Shelly Richardson

*if and attendee's identity was unclear, *the name appears as they entered it into WebEx*

I. **Call to Order** – Amber Smock, chairperson of the subcommittee, called the meeting to order at 3:00 PM.

II. **Review and approval of meeting minutes from November 4, 2021**— Kathy Carmody moved to approve the minutes from November 4, 2021. Ann Lundy seconded the motion, which was approved by the subcommittee.

III. **Public Comment** – Several members of the public offered comment to the subcommittee: Bruce Carmona, Januario Ortega, Kira Meskin, Andrea Kindseth, Barb Pritchard, Maureen Howard, Kathy Weiman, Allan Bergman, and Becky Ogrodny. Comments conveyed issues and recommendations related to home and community-based services (HCBS) for individuals with disabilities, including:

- Difficulty finding caregiver, homemakers, personal assistants, and nursing services, with evenings and weekends cited as a unique challenge.
- Services covered by the Waiver for Persons who are Elderly may not meet all the needs of an older adult with a disability; one commenter recommended expanding services covered by that waiver.
- Persons with disabilities may have limited access to information and technology.
- Respite care is essentially important and needs additional funding.
- Impact of caregiver strain makes access to home and community-based services critical.
- Wages for HCBS caregivers are not competitive with higher wages in other sectors.
- Individuals receiving HCBS and other agencies serving them encounter challenges working with managed care.
- Person-centered planning is not occurring with enough regularity.
- There is a need for more robust community-based mental health rehabilitation services.

Additional public comment was received in written format and is attached as an appendix to these minutes.

IV. **Update on PUNS list –** DHS-DDD Director Allison Stark presented to the committee on the system of care for individuals in Illinois with developmental disabilities, including an overview and update on the PUNS list. Her presentation is attached as an appendix to these minutes.

V. **HCBS Settings Rule –** Emily Brigman from HFS presented to the committee on the HCBS Settings Rule. Her presentation is posted here: https://www2.illinois.gov/hfs/SiteCollectionDocuments/MACSTP01062022.pdf .

VI. **Program of All-Inclusive Care for the Elderly (PACE)** – Lisa Gregory from HFS presented to the committee on PACE. Detailed information about plans for the PACE model in Illinois can be found here: https://www2.illinois.gov/hfs/MedicalProviders/pace/Pages/default.aspx .

VII. **Discussion –** Subcommittee member discussion ensued. Multiple members expressed appreciation for both the presentations and especially for the individuals making public comment. Others noted their broadening awareness of services across all waivers, not only those for which they already have specific and focused knowledge. Finally, Money Follows the Person was cited as a potential means of expanding access to home modifications as well as supporting community integration for individuals leaving or being diverted from institutional settings.

VIII. Identify agenda focus for March meeting – Chairperson Smock asked subcommittee members to send future agenda recommendations to her by January 31, 2022.

Gabriela Moroney read the dates for the remainder of the subcommittee meetings in 2022 into the record: March 3, May 5, July 7, September 1, and November 3. All meeting times are from 3-5 PM.

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

Illinois Department of Human Services Division of Developmental Disabilities DDD Update for MAC Community Integration Subcommittee

1/6/2022

Allison Stark
Director, Division of Developmental Disabilities

Help is Here

IDHS

DDD System Overview

FY 22 Budget: ~ $2.3 billion

Staff Total: ~ 4,100

- Administers 3 Home and Community Based (HCBS) Medicaid Waivers:
  - Adults with Developmental Disabilities (DD) Waiver
  - Children’s Support Waiver
  - Children’s Residential Waiver
- Funds and provides placement for Intermediate Care Facilities for Individuals with I/DD (ICF/DD)
- Operates 7 State Operated Developmental Centers (ICF/DD)
- Funds grant programming including Respite, Epilepsy programming, etc

Illinois System Challenges

Past (and current) system challenges:

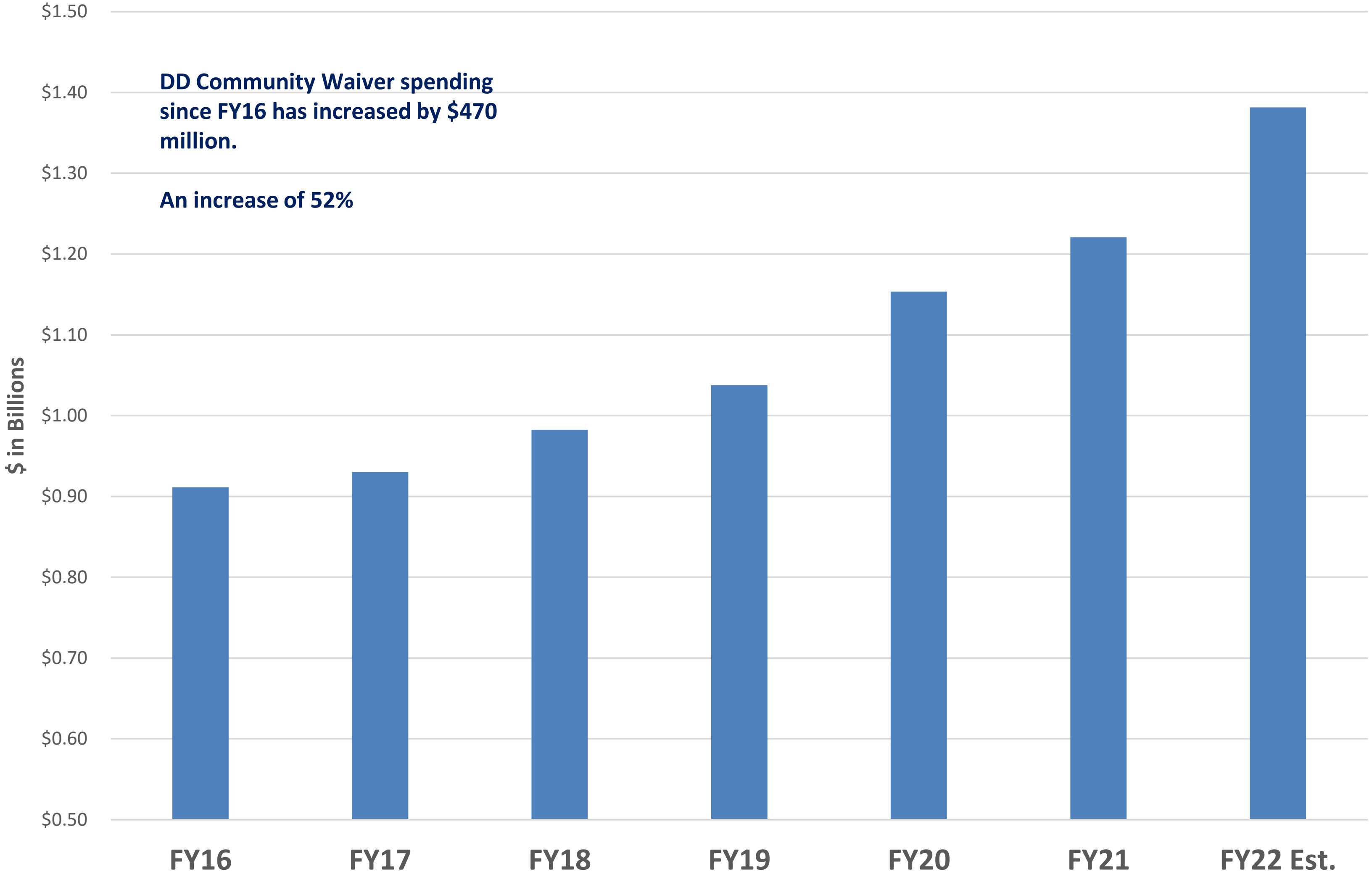
- Ensuring appropriate rates for services and appropriate “buying power” for individuals using self-directed supports
- Impacts of the nationwide staffing crisis
- Impacts of COVID-19 on the service system
- Increasing service quality during this significant period of instability
- Support for children and adults that are dually diagnosed with I/DD and behavioral health needs and/or high medical needs
- Support for children and adults with specific needs that require more individualized supports
- Moving the system to being more person centered, individualized and self-directed

Illinois System Data Points

We have invested approximately $470 million in new Home and Community Based Services spending since FY 16 (52% increase).

- In FY 16, we were spending just over $900 million on HCBS services and supports.
- In FY 22, we are estimated to spend close to $1.4 billion on HCBS services and supports.

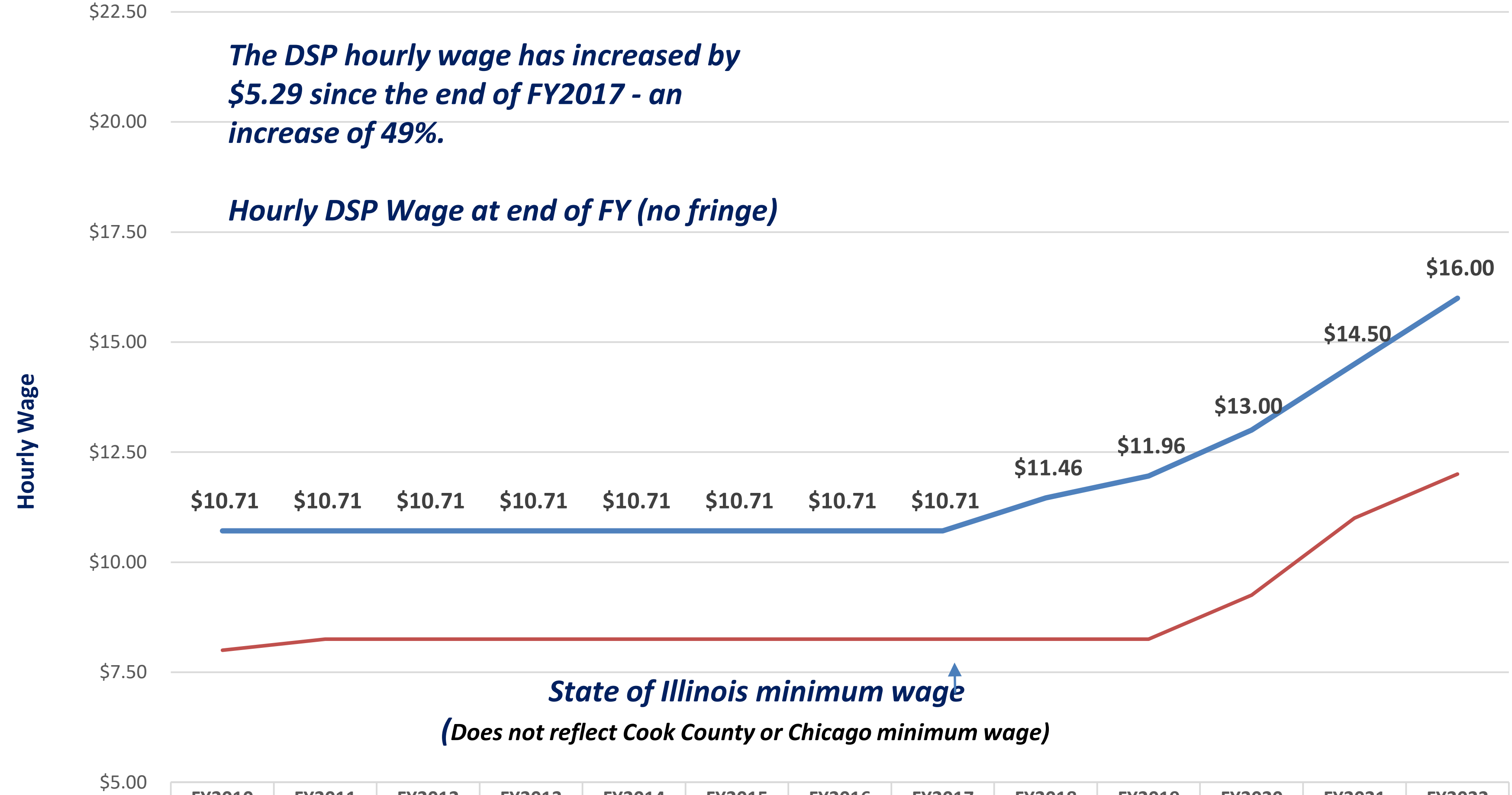
DD Community Waiver Spending
FY16 to FY22



DD Community Waiver spending since FY16 has increased by $470 million.

An increase of 52%

Division of Developmental Disabilities
DSP Hourly Wage
FY2010 to FY2022



The DSP hourly wage has increased by $5.29 since the end of FY2017 - an increase of 49%.

Hourly DSP Wage at end of FY (no fringe)

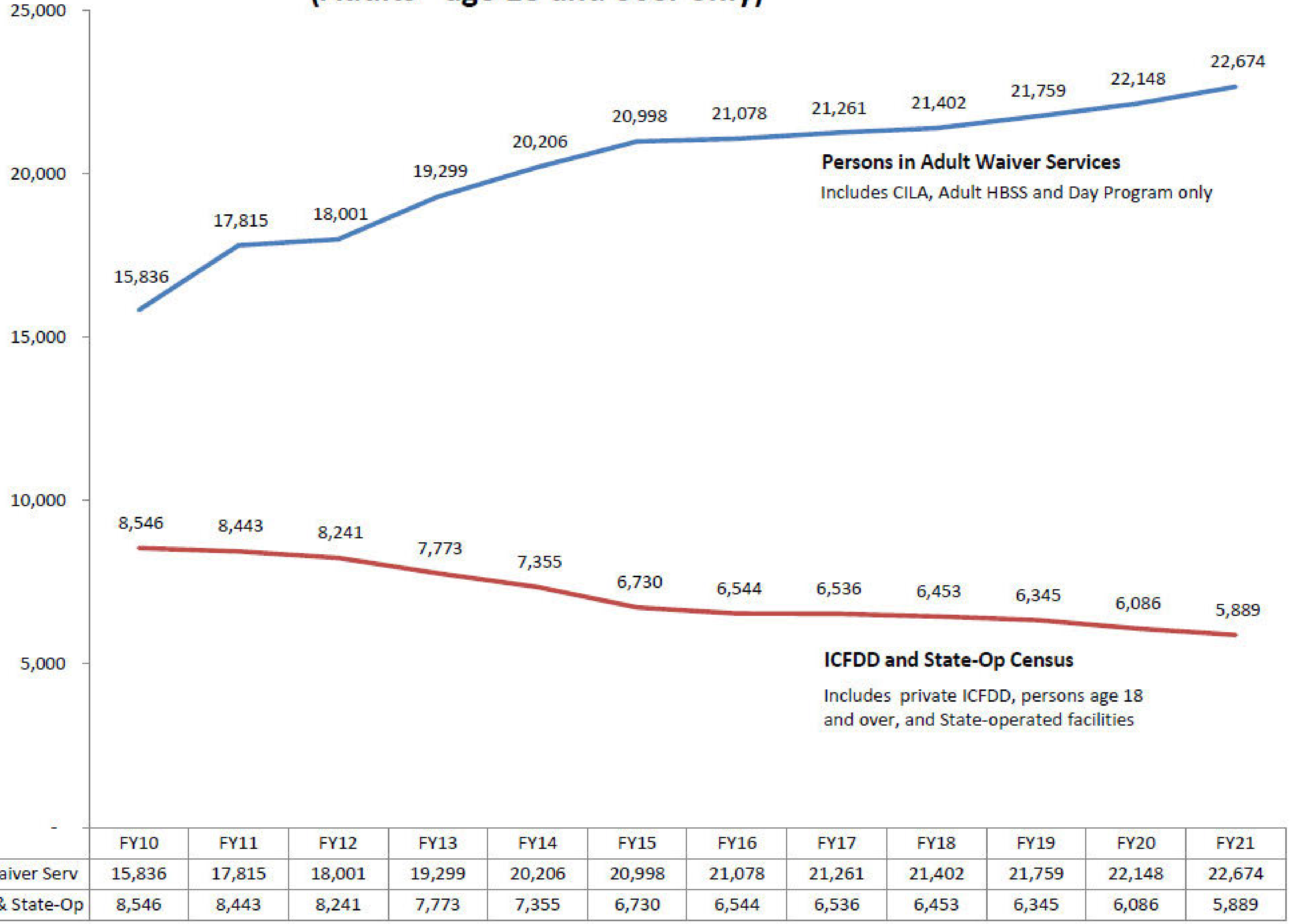
State of Illinois minimum wage

(Does not reflect Cook County or Chicago minimum wage)

	FY2010	FY2011	FY2012	FY2013	FY2014	FY2015	FY2016	FY2017	FY2018	FY2019	FY2020	FY2021	FY2022
DSP Hourly Wage	$10.71	$10.71	$10.71	$10.71	$10.71	$10.71	$10.71	$10.71	$11.46	$11.96	$13.00	$14.50	$16.00
Illinois Min. Wage	$8.00	$8.25	$8.25	$8.25	$8.25	$8.25	$8.25	$8.25	$8.25	$8.25	$9.25	$11.00	$12.00

Adults in Community Waiver vs. Large Facilities
End-of-Year Persons
FY10 to FY21
(Adults - age 18 and over only)

Since FY10 persons in adult waiver services have increased by 43% while SODC & ICFDD census has decreased by 31%.



Persons in Adult Waiver Services

Includes CILA, Adult HBSS and Day Program only

ICFDD and State-Op Census

Includes private ICFDD, persons age 18 and over, and State-operated facilities

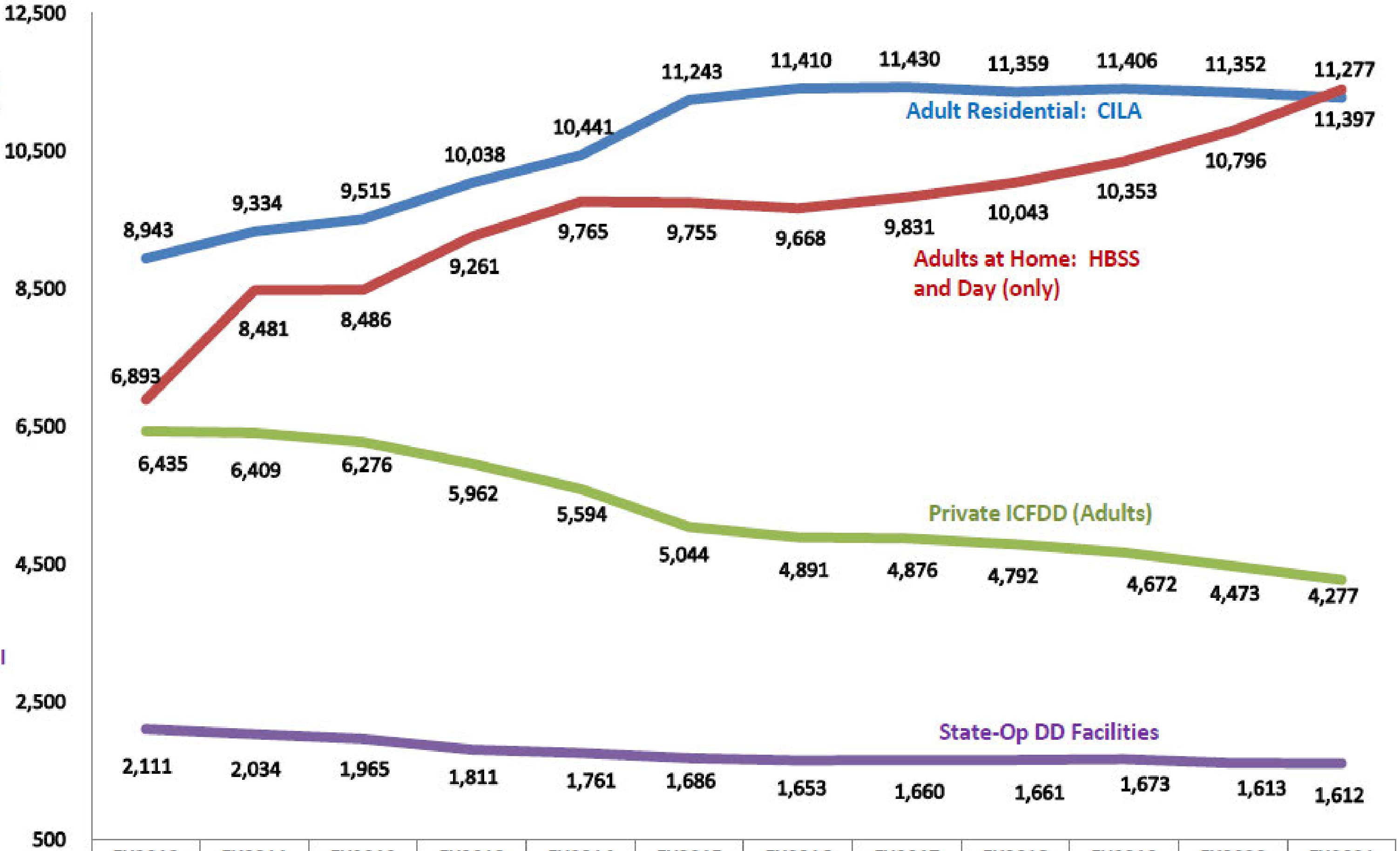
	FY10	FY11	FY12	FY13	FY14	FY15	FY16	FY17	FY18	FY19	FY20	FY21
Adult Waiver Serv	15,836	17,815	18,001	19,299	20,206	20,998	21,078	21,261	21,402	21,759	22,148	22,674
ICFDDs & State-Op	8,546	8,443	8,241	7,773	7,355	6,730	6,544	6,536	6,453	6,345	6,086	5,889

Adults with Developmental Disabilities by Living Arrangement

End of Year Persons

FY2010 to FY2021

(Adults - age 18 and over only)



Adult Residential includes CILA codes: 60D, 61D, 65H.

Adults at home include HBSS (adult, type H) and those receiving day program only (type D)

Private ICFDD includes all categories of DD long term care - age 18 and older. Includes MCDDs.

State-Op facilities include all 7 facilities. Choate is only the DD population.

	FY2010	FY2011	FY2012	FY2013	FY2014	FY2015	FY2016	FY2017	FY2018	FY2019	FY2020	FY2021
Adult Residential: CILA	8,943	9,334	9,515	10,038	10,441	11,243	11,410	11,430	11,359	11,406	11,352	11,277
Adults at Home: HBS & Day Pgm (only)	6,893	8,481	8,486	9,261	9,765	9,755	9,668	9,831	10,043	10,353	10,796	11,397
Private ICFDD (age 18 & over only)	6,435	6,409	6,276	5,962	5,594	5,044	4,891	4,876	4,792	4,672	4,473	4,277
State Operated Facility	2,111	2,034	1,965	1,811	1,761	1,686	1,653	1,660	1,661	1,673	1,613	1,612

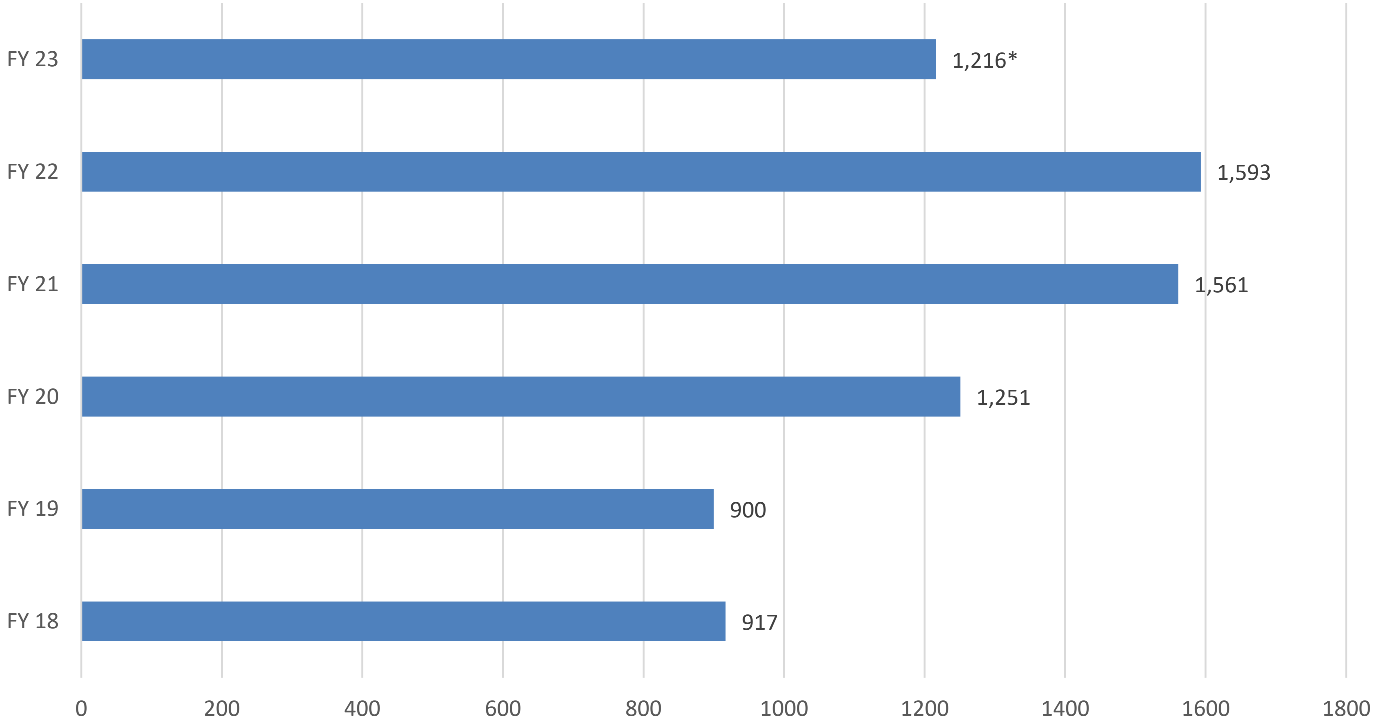
PUNS List

- The State’s database that registers children and adults with I/DD who want or need HCBS waiver funded DD services
- As funding is available, based on appropriation, people are selected from PUNS for services
- There are two categories of people on the PUNS List:
  - Seeking Services: Children and adults who currently need or desire services – PUNS selections are made from the Seeking category only
  - Planning for Services: Children and adults who do not currently need or desire services but may in the future

PUNS List

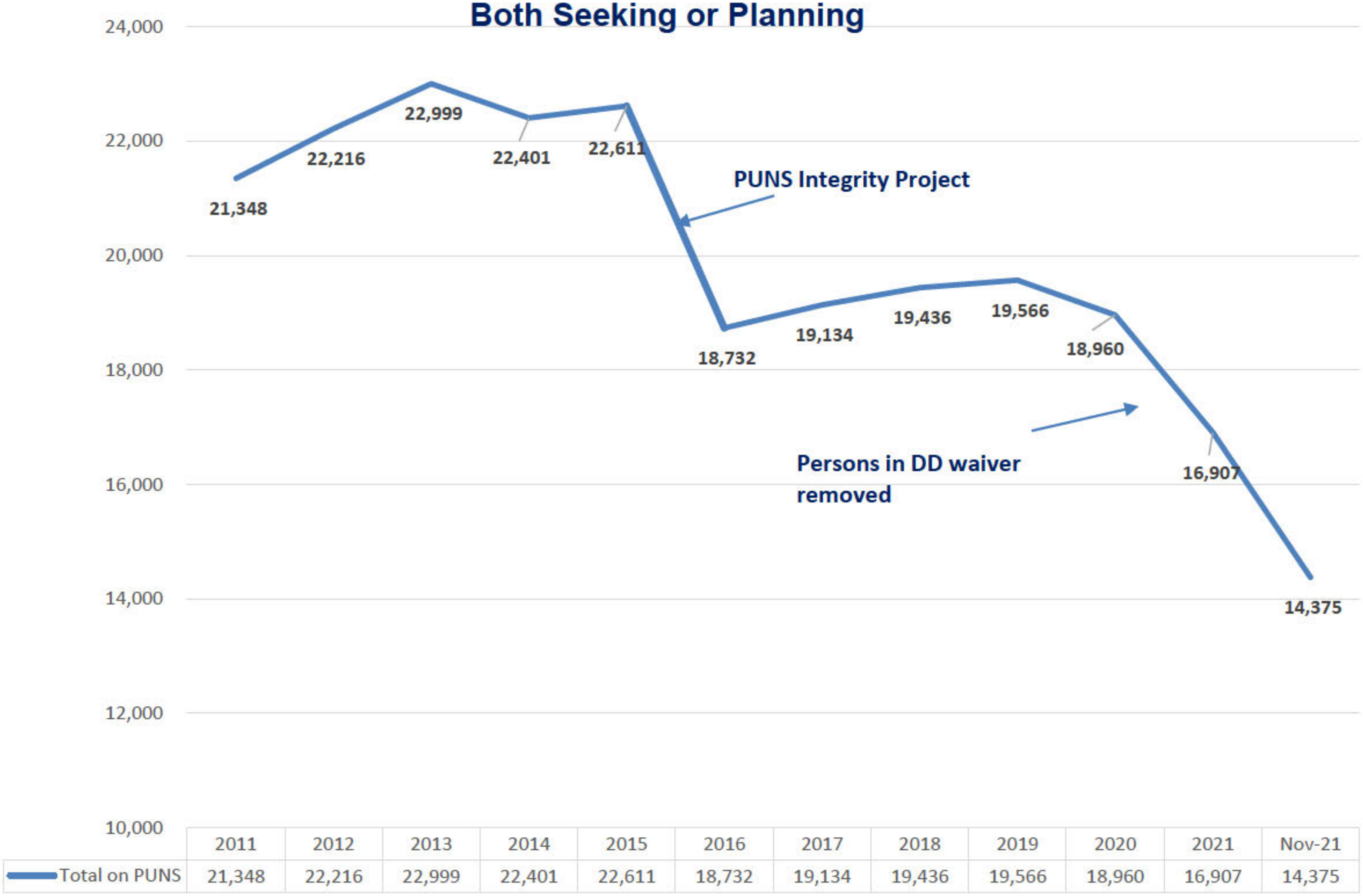
- Since 2018 "early notice letter" notifies individuals of their anticipated selection 6 months prior to official PUNS pull notification
- Children and Adults with I/DD and their families work with their local Independent Service Coordination (ISC) Agency to register on the PUNS
- Per the Ligas Reasonable Pace requirement, for FYs 21–25, the State must have at least 630 individuals from the PUNS List enter into services each year. After FY 25, no individual can wait more than 60 months (5 years) in the seeking services category. We are currently exceeding these requirements!

Individuals Selected for Services (PUNS pulls)
FY 18 – FY 23



***Indicates number of pre-selection letters sent**

Total Active Persons on PUNS
Adults & Children
Both Seeking or Planning



PUNS Integrity Project

Persons in DD waiver removed

	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	Nov-21
Total on PUNS	21,348	22,216	22,999	22,401	22,611	18,732	19,134	19,436	19,566	18,960	16,907	14,375

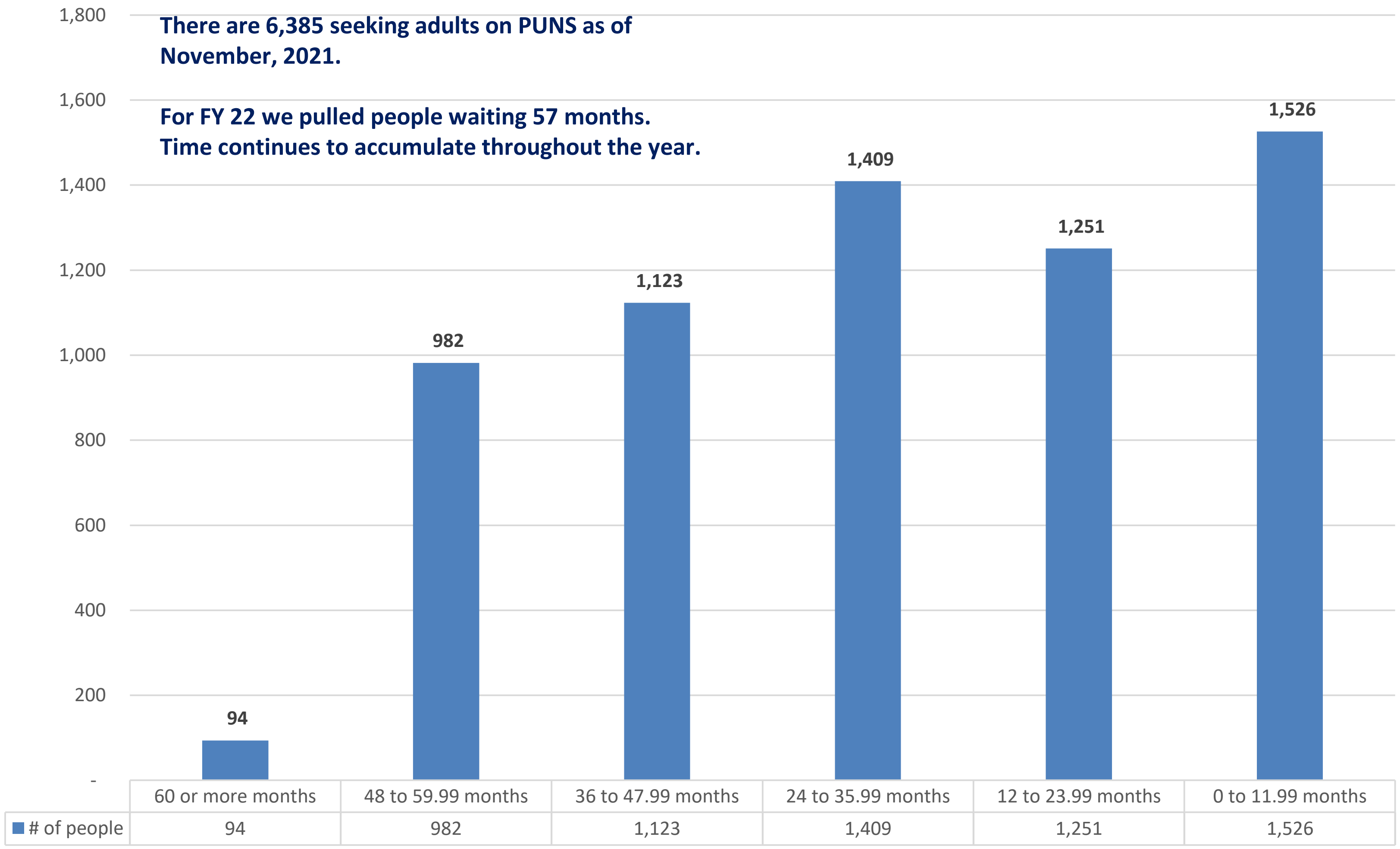
Illinois System Data Points

Our PUNS number continues to be inflated due to our tracking system. Most states only count those that are eligible to be selected and seeking services.

The 14,375 continues to reflect 5,020 children and adults in the planning category/already selected category.

There are actually 9,355 (6,385 adults and 2,970 children) that want services and are in the seeking category.

Eligible Adults on PUNS and their time waiting while seeking services as of November 2021



There are 6,385 seeking adults on PUNS as of November, 2021.

For FY 22 we pulled people waiting 57 months.
Time continues to accumulate throughout the year.

	60 or more months	48 to 59.99 months	36 to 47.99 months	24 to 35.99 months	12 to 23.99 months	0 to 11.99 months
■ # of people	94	982	1,123	1,409	1,251	1,526

Help is Here

IDHS

FY 22 Initiatives

- HCBS Waiver Amendment & Waiver Renewals
- Supports Waiver
- Person Centered Planning Process
- System Capacity Assessment for Higher Need Individuals
- Settings Rule Implementation
- Competitive Integrated Employment Expansion
- Supportive Housing Models Expansion
- Implementation of the FY 22 budget

Thank You!

Questions?

From: Januario <[redacted]>
Sent: Tuesday, December 21, 2021 1:00 PM
To: Moroney, Gabriela M.
Subject: [External] MAC CI Public Comment

Categories: CI

Dear Moroney,

Comment #1: Faster service via phone and in person.

Sincerely,

Januario Ortega

Sent from [redacted] for Windows

Moroney, Gabriela M.

From:	Parks, Teresa
Sent:	Monday, January 3, 2022 1:25 PM
To:	Moroney, Gabriela M.
Subject:	written testimony for community integration
Categories:	CI

I am the parent of a soon-to-be 30 year old son with Down Syndrome who continues to live at home with a limited # of hours for a personal assistant to help him while both parents work. Our son works a few hours per week at a community job. His personal assistant helps during the daytime while we are at work, and, as parents we provide caregiving in the evenings and on the weekends. Some gaps/needs we have experienced include the following:

1. When my son was transitioning out of education, the school provided no information about adult services. Instead, they simply invited the congregate day provider (an option that we did not want) to attend his IEP. More needs to be done to connect students with disabilities, while still in school, to a range of options to decrease delays in accessing services.
2. While my son was in school, the school did involve the DRS STEP program which led to community employment after he left school. However, I know of many parents whose schools do not engage this program. More needs to be done to facilitate student access to the STEP program.
3. DRS funding for job coaching is time-limited but many, including my son, would benefit with a longer time with a job coach. This might also facilitate increased employment opportunities. In addition, more needs to be done in the area of customized employment to facilitate even more employment opportunities for my son and others.
4. Illinois needs to take steps to transition to supported living like other states have. Supported living is where individuals choose where they want to live – with their parents, in an apartment, in their own home, etc. Then, services come to them based on their needs whether they need 24 hours supports or a few hours per week. Illinois' structure for DD services is heavily reliant and stuck on congregate living/work options and movement toward more progressive approaches seems very, very slow. Congregate living would be detrimental for my son from a health perspective and due to sensory issues. We have a limited amount of personal assistance hours that would not cover his needs should we not be able to provide evening and weekend care. So, supported living in one's home of choice with increased access to support hours would offset the difficult choice of an undesired congregate living arrangement or ongoing caregiving by aging parents.
5. In my work in the field of disabilities, I know that persons with more intense behavioral needs face greater barriers and limited access to services. Access to more behavioral supports as well as crisis supports are warranted for these folks.

Thank you for this opportunity to share testimony.

Teresa Parks, Parent Member of the ICDD, Metamora IL.

Moroney, Gabriela M.

From: [redacted] <[redacted]>
Sent: Monday, January 3, 2022 5:51 PM
To: Moroney, Gabriela M.
Subject: [External] MAC CI Public Comment

Categories: CI

To who it may concern,

I would like to submit a public comment for the The Medicaid Advisory(MAC) Community Integration Subcommittee meeting.

My son is apart of the DSCC MFTD program because he has Spinal Muscular Atrophy Type 1. Even though he has been allotted nursing care, with the current nursing shortage, we are unable to use this benefit. I believe that HFS should adapt the program of paid parent caregiver. I am the sole parent in this situation and I simply cannot hold traditional employment due to my sons therapy and appointment schedule. The only income we receive is his SSDI. We are lucky to receive monthly food stamps. Having the paid parent caregiver program would allow me to be able to set aside money so that I can eventually look for an ADA compliant home for his wheelchair. I would be able to afford gas for transportation. I could afford to make sure my heat and electricity stay on. I could afford his equipment that is needed for his therapies. I would do any sort of training and take any necessary steps in order to be eligible for this program.

And I do know that this would not only effect my family, but mainly families who are all barely surviving right now.

Please take this option into consideration.

Thank you
Michelle Tynski

Moroney, Gabriela M.

From:	Laura Zacharski <[redacted]>
Sent:	Monday, January 3, 2022 7:34 PM
To:	Moroney, Gabriela M.
Subject:	[External] MAC CI Written Comment
Categories:	CI

As a Transition teacher for students with significant cognitive disabilities including health needs and behavioral needs, I continue to see families struggle to find community participation and support that will accept their child requiring total support.

Laura Zacharski
SASED Transition Teacher
[redacted] (school phone)
[redacted] (Google voice)

Moroney, Gabriela M.

From:	Ana Cruz <[redacted]>
Sent:	Monday, January 3, 2022 11:57 PM
To:	Moroney, Gabriela M.
Subject:	[External] HCBS testimony
Categories:	CI

Good morning Gabriela,

Thank you for let you know our experiences over the years in this program, we send you our writing testimony:

- Which groups of Medicaid enrollees are not fully served by Illinois Medicaid-funded home and community-based services? What barriers are they experiencing?

The Children community. Most of the preferences are for services for adults and there are just few services available for children, however after to insist on requesting it, the paperwork and requirements are slower and more cumbersome to delay as much as possible the service or request, in addition to the almost no interest in helping clients from Latino families belittling their situation or understanding capacity assuming that that families have “low cultural level” under the pretext of just their "language".

- Where and with which populations is demand for home and community-based services rising?

In Southern Illinois for services related of PSW, ABA, OT, SLP or any specialist that could provide services through the waiver because nobody wants to be involved or unknown the HBS waiver.

- 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?

Yes, in our experience we had to wait more than 3 years in the paperwork and process to request specifically a safety fence for our son, the delays were because the ISCs were not proactive and able to provide the accurate information and well communication between providers, agencies, and client. There are no penalties or incentives to do their work.

- What are some ideas for expanding access to Illinois Medicaid home and community-based services?

Agencies and ISCs must be better prepared and willing to serve the client in their request for service, instead of complicating it and obstructing this process with the intention of delaying or denying the requirements, thereby causing them to have start all over again re-request each time there is a rejection. Agencies must work together along with the client, not just for “a client” to cover their schedule time, they have to be respectful with the clients who decided to be "self-Independent" and DHS has to provide same information and training as provide to Agencies, also the requirements of the processes and services must be clearer and more precise in such a way that they can be fulfilled at once and without delays. The training for Agencies and families must be stated in the law to be provided in no more than 30 calendar days as well as the services to be provided in no more than 60 calendar days, stating that if this is not fulfilled timely, the HBS must deliver the resources to the parent/guardian of the client to have the services he/she needs in no more than 60 days with any private certified provider or with any private health insurance in order to obtain the required service, but this service must be provided to the client.

Thank you,

Ana and Martin Cruz

Moroney, Gabriela M.

From: msm62184 <[redacted]>
Sent: Tuesday, January 4, 2022 7:59 AM
To: Moroney, Gabriela M.
Subject: RE: [External] MAC CI Written Comment

Categories: CI

My apologies, my signature did not save. My name is Monica Mitchell

Sent from my T-Mobile 4G LTE Device

-------- Original message --------
From: "Moroney, Gabriela M." <Gabriela.M.Moroney@Illinois.gov>
Date: 1/3/22 7:37 PM (GMT-06:00)
To: [redacted]
Subject: RE: [External] MAC CI Written Comment

Hello! I'd be happy to provide your written comment to the subcommittee and include it in the record of the meeting. Is there a reason you have not provided your name? I'm not certain we can include anonymous comments but if that is your preference, I will check with our legal folks and include if permitted.

Gabriela

From: [redacted] <[redacted]>
Sent: Monday, January 3, 2022 6:43 PM
To: Moroney, Gabriela M. <Gabriela.M.Moroney@Illinois.gov>
Subject: [External] MAC CI Written Comment

Good evening

I am a disability care coordinator with County Care and wanted to provide feedback on the following.

1. Which groups of Medicaid enrollees are not fully served by Illinois Medicaid-funded home and community-based services? What barriers are they experiencing?

Individuals with mental health, intellectual disabilities, and substance use are not being fully served due to engagement barriers. The DON screening does not address mental health or intellectual delays and focuses on physical and medical needs.

2. Where and with which populations is demand for home and community-based services rising?

The south and west side of Chicago, with few staff in the area to meet the needs and current demands to support the population. There is an increase in clients with complex medical needs, mental health, developmental delays, and substance use concerns.

3. 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?

I believe there are delays with receiving the services. We need to be provided with current and correct contact information for new members, including the current POA or guardian. If it is a transfer from a different MCO we should receive the previous SP within 30 days. Barriers exist with homemaker services due to language barriers and engagement concerns. Members often do not answer phones to engage with service providers. The biggest delay relates to PA services, as it takes a long time for the provider to be approved, paid, and onboarded. MCO's bare the burden of initial engagement, which leads to confusion because we are not state employers, or aware of state HR polices and rules. This also impacts our ability to provide care to medically complex members and support care coordination. It also presents as a conflict as we support the member and not the provider and can lead to boundary concerns in the event that we did not place abuse and neglect calls against the provider on the members' behalf. The state should be held accountable to manage the PA process, so that disabled individuals can be fully supported by their care coordinators. Care coordinators specifically selected this job to help underserved, vulnerable members of society improve their health, autonomy, and dignity in the community. We went to school and pursued training to excel at this, so why are we being expected to be HR assistants to the state, when we cannot access anything needed to approve the IP provider, or issue payment for services rendered? It is not an effective method to manage our time, and is a waste of resources and tax dollars to have MCOs manage what the state should be managing.

4. What are some ideas for expanding access to Illinois Medicaid home and community-based services?

Setting caseload limits for care coordinators given the complex needs of the members.

Having different levels of care coordinators (I, II, III, IV, V) which each increasing level having more credentials and a smaller caseload to manage complex cases.

Contract to an outside agency to manage the PA process because I don't think the state can effectively manage the process. It should not take 7-8 months for an IP provider to be approved and another 4 months for them to be paid. It is completely unacceptable and probably would not occur if we were not dealing with vulnerable members of society. Please hold these state workers accountable. Let them go a year without pay so they can emphasize with the vulnerable members they do not fully support.

Thanks and I hope you can make changes on the last two items. It would change lives.

Moroney, Gabriela M.

From:	krescene beck <[redacted]>
Sent:	Tuesday, January 4, 2022 2:11 PM
To:	Moroney, Gabriela M.
Cc:	Robert Peterson
Subject:	[External] MAC CI Written Comment
Categories:	CI

My name is Bob Peterson, and I live in the Quad Cities area. I have a developmental disability. I receive HCBS services, and I am served by a CILA (Community Integrated Living Arrangement) provider.

HCBS is about access to and being in the community.

Having HCBS services and being on a spend down prevents people from getting competitive community employment. People should be able to choose to work part time or full time and have the opportunity to save their money without worrying about losing benefits. The limits need to be raised so that people with developmental disabilities can make money and feel like part of society without losing benefits. We should have equal opportunity as non-disabled people do to work, make money and save money. Earning money shouldn't come with a penalty. People who receive HCBS services want to advance in their lives, maybe one day buying an accessible van or a home. Having a low asset limit spend down prevents us from realizing our dreams.

Let's figure out a way for people with developmental disabilities who receive HCBS services to have a better life. If you want people to be in community, provide the necessary support and services for them to be truly successful and part of their communities.

[redacted]
Pronouns: she/her. Please tell me yours.
Blue Tower Solutions, Inc.
[redacted]
[redacted] (direct line)
[redacted] (direct e-mail)

Discover your passion. Live your purpose. Celebrate your journey.

Save the Waiver
Kids belong at HOME!

MFTD Waiver Families
www.mftdwaiver.org
mftdwaiver@gmail.com

January 4, 2022

Illinois Medicaid Advisory Committee
Subcommittee on Community Integration

Re: Subcommittee meeting on January 6, 2022

Dear Subcommittee on Community Integration:

This testimony is on behalf of MFTD Waiver Families, a support and advocacy group that includes approximately 500 parents, guardians, and individuals who participate in Illinois' Medically Fragile, Technology Dependent (MFTD) Waiver.

MFTD Waiver Families appreciates the opportunity to share with the subcommittee the challenges currently faced by the approximately 1000 participants in the MFTD Waiver and their families. Most of these participants have a combination of disabilities and complex medical conditions and require significant medical technology, including ventilators, tracheostomies, oxygen, feeding tubes, or IV lines.

This testimony will address the following issues currently affecting individuals and their families in this waiver program:

1. Shortage of private duty nurses
2. The addition of paid parent caregiver services
3. Additional services for participants over the age of 21
4. Palliative care services for participants and their families

Shortage of Private Duty Nurses

Private duty nursing is by far the most critical component of the MFTD Waiver, and is the primary service allowing individuals to live at home, attend school, and participate in their communities. This service is provided to MFTD Waiver participants either as a waiver service or as part of the state plan package, depending on the age of the participant.

As most of the participants in the MFTD Waiver are children and young adults, it is important to address holistically the impact of services on the entire family unit in order for full community integration to be achieved. In addition to helping children integrate into the community, private duty nursing also allows parents and guardians to continue to work and participate in their communities by providing skilled nursing care to children while parents/guardians work and sleep.

Shortages in nurses to fill Medicaid-approved private duty shifts have occurred for years due to a variety of factors, including pay rates and lack of training. During the pandemic, these shortages have become extreme, primarily due to the availability of other higher-paying jobs for nurses.

These recent shortages have had a profound effect on community integration for the entire family unit. Currently, there are numerous participants who have 0% of their nursing shifts filled, meaning parents are taking care of individuals with ventilators and feeding tubes 24 hours a day without any respite. Most other participants have less than half of their nursing shifts filled. Forcing family caregivers to provide this unexpectedly high burden of skilled care is not safe for individuals in the MFTD Waiver, threatens participants with institutionalization, and severely limits community integration.

A large percentage of children are unable to attend school or participate in other community activities because they do not have nursing in place. Similarly, a large percentage of parents have had to leave the workforce to provide skilled nursing care to their children due to these nursing shortages.

When family members are providing the bulk of skilled nursing care, community integration becomes near impossible. Family members are stretched beyond their physical and emotional capabilities, and are no longer able to provide a level of care beyond sheer survival for their children. Individuals become high risk for permanent hospitalization of institutionalization due to the severity of their medical needs.

Note that for the majority of individuals in the MFTD Waiver (those under the age of 21) home nursing is a mandated EPSDT service that must be provided and arranged. The consent decree currently in place for *OB v. Eagleson* dictates numerous steps to address the private duty nursing shortage, many of which are currently not being implemented.

We suggest the following remedies to improve private duty nursing, thus expanding the ability of individuals with medical technology to integrate into the community:

1. Fully implement a robust Staffing Support Team, as required by the OB Consent Decree, to assist families in finding nurses and agencies able to care for their children. Currently, this “team” exists more on paper than in reality and has provided little assistance to families. Broadening the current waiver service entitled Placement Maintenance Counseling Services could perhaps help cover the costs of this service.
2. Allow flexibility in pay rates for difficult-to-staff cases, including increased rates for night, weekend, and holiday shifts, and increased rates for high-acuity cases.
3. Continue to allow parents who are LPNs or RNs to be paid to care for their children, including minor children, under supervision of a home nursing

agency. This service was added as part of Appendix K and is in the process of being made permanent.

4. Allow parents who are CNAs to be paid to care for their children, including minor children, under supervision of a home nursing agency.
5. Put in place a paid caregiver program (see next section).
6. Mandate a pass-through percentage of the Medicaid reimbursement rate so that nurses receive an adequate portion of the hourly reimbursed rate. Currently, nursing agencies have pocketed most of the reimbursement rate increase provided through the OB Consent Decree. Pass-through amounts are standard in other HCBS programs in Illinois.
7. Annually increase Medicaid reimbursement rates for private duty nursing in conjunction with Cost of Living Adjustments.
8. Provide paid training programs for nurses to learn the skills required for homecare. Many nurses have never cared for individuals with tracheostomies, ventilators, or feeding tubes and need to be specifically trained to provide this type of care.
9. Reimburse the cost of training nurses for specific cases. Typically, agencies are not reimbursed when one nurse on a case trains another because Medicaid will not pay for two nurses simultaneously. Perhaps creative use of the Nurse Training waiver service could overcome this barrier.
10. Continue to allow overtime for nurses, which was put in place during the pandemic by Appendix K.
11. Ensure nurses are continuously provided with appropriate PPE, as well as other workplace safety needs, such as hand sanitation and medical-grade soap.
12. Provide nurses access to state-based or union-based health insurance pools to make nursing positions more attractive.
13. Compile and publicly distribute the data required by the OB Consent Decree, particularly the percentage of filled and unfilled nursing shifts.

Paid Parent Caregiver Services

Realistically, the state is nowhere near to meeting its EPSDT burden of arranging and providing all approved home nursing shifts to children who require them. As a stop-gap measure to allow children and families to continue to live at home in the community, families believe a paid parent caregiver will help to ease this burden. The state and DSCC are in the process of exploring this idea, using approved pandemic funds, and the concept is strongly supported by families in the program.

In such a program, trained family caregivers are paid to provide care for their own children, with monitoring and documentation requirements. Models for this type of program include the IHSS programs in California and Colorado, several unique programs in Minnesota, and parent-as-CNA programs in Colorado and Arizona.

This type of program allows participants to remain living at home and supplements their families financially for care provided, since many parents have been forced to quit their jobs due to a lack of nursing services for their children.

Families urge the state to ensure that this program is separate from private duty nursing, as it should not be used in any way to restrict, replace, or deny medically necessary nursing care that the state should be providing to participants. Families also encourage the state to make the program optional, as some parents or guardians lack the time or ability to participate.

Additional Services for Participants Over Age 21

Several years ago, the MFTD Waiver was expanded to serve individuals of all ages, as long as participants enter before the age of 21. Unfortunately, the waiver services currently provided through the MFTD Waiver were not updated for this expanded population. This leaves those over age 21 in a dilemma: if they stay in the MFTD Waiver in order to continue receiving appropriate private duty nursing services, they are unable to participate in adult services, such as day programs and employment services.

Adding these new waiver services to the MFTD Waiver will provide a complete community integration package for these individuals, allowing them full access to the community as college students, workers, and community participants. As there are not a large number of individuals over the age of 21 and not all participants will require these services, the increase in cost for these services is minimal.

Finally, we want to ensure that participants who attend day, vocational, college, and employment services are permitted to bring along their 1:1 private duty nurse, as that is the only way that many individuals are able to participate in these programs.

We strongly urge the following services to be added to the MFTD Waiver:

- Supported Employment
- Developmental Training
- Prevocational Services
- Adult Day Programs
- Extended State Plan Therapy Services (speech, occupational, physical, and behavioral)

Palliative Care Services

As many participants in the MFTD Waiver are extremely medically complex, it is not unusual for them to have life-limiting conditions. A significant portion of MFTD

Waiver participants pass away each year. In 2021, the Illinois legislature passed the Pediatric Palliative Care Act, which allows Medicaid to reimburse for standard palliative care services. These services include but are not limited to intermittent nursing visits, expressive therapies, child and family counseling, and bereavement counseling. Families request that these palliative care services be integrated into the MFTD Waiver program to help support participants and their families.

MFTD Waiver Families sincerely thanks the Subcommittee on Community Integration for the opportunity to provide this feedback. We hope it will bring much-needed changes to the program in the very near future.

Sincerely,

Susan Agrawal
Founder, MFTD Waiver Families

Moroney, Gabriela M.

From: Sherry Healey <[redacted]>
Sent: Tuesday, January 4, 2022 4:16 PM
To: Moroney, Gabriela M.; [redacted]
Subject: [External] MAC CI Written Comment

Categories: CI

Dear Gabriela and Amber,

Thank you for the opportunity to provide feedback regarding the HCBS waiver.

I serve as the Board President of Community Access Naperville, President of CAN Consulting, Chairperson of the IDHS Autism Task Force Adult Services Subcommittee, and parent to Michael, a recipient of HCBS.

Groups not fully served by HCBS include those with high support needs (more than 1:6 staff:participant ratio), those with a developmental disability without intellectual disability, and those seeking residential services.

Recipients of Home Based Services have the ability to hire a parent as a personal support worker, and then the parent can use the funding to most appropriately meet the needs of the individual served. As a CILA resident, this flexibility of funding does not exist. CILA daytime funding can only be used to pay for licensed Community Day Services. While CDS programs are working hard to transition to community-based programming, individuals with higher support needs (i.e. 1:3 staff:participant ratio), or varied interests, do not have the opportunity for person-centered community integration.

Individuals on the autism spectrum with IQs above the limit to be considered Intellectually disabled are not eligible for services under the HCBS waiver. An individual with a Developmental Disability that impacts their ability to work and care for themselves independently are denied much-needed services and should be included in HCBS. While their needs may not be as extensive as those who need 24/7 support, they are often in need of counseling, social skills support groups, or long-term supported employment services. Employment challenges for these individuals are generally not job skills related, but soft skills that may not present significantly until they have been on the job for several months. Unfortunately, DRS funding is time-limited.

CILA capacity is significantly below demand. Personally, we have been searching for CILA placement for over 3 years. Multiple agencies have advised our ISC that they do not have any openings, and one agency considered but rejected Michael due to epilepsy. We have been in talks with an agency regarding opening a new home (an hour away from our family home) for two years. Of the 6 staff needed, they have been able to hire only one.

As minimum wage increases in Illinois, the requirement for earnings to remain below Substantial Gainful Activity in order to remain eligible for HCBS is becoming more of a challenge. Other states (e.g. Tennessee) have set a higher earnings limit. Many HCBS recipients can work more hours, but are limited by their need to remain eligible for HCBS, especially for residential support. Unbundling SSI/SSDI and CILA funding should also be considered, in order for CILA residents to utilize housing subsidies and encourage employment without loss of revenue for the agency.

Again, I appreciate the opportunity to give input.

Best regards,
Sherry Healey

P.S. I would like to attend the meeting on Thursday. Can you please send the link?

Moroney, Gabriela M.

From: Gayle Griffin & [redacted] <[redacted]>
Sent: Tuesday, January 4, 2022 4:31 PM
To: Moroney, Gabriela M.
Subject: [External] MAC CI Written Comment

Categories: CI

Good afternoon!

Thank you for providing an opportunity to submit a written comment to the Medicaid Advisory Board. Upon reading the questions that are of interest to the MAC Board, I felt this was an avenue to address my request. I have also spoken with local and state legislators in regards to this matter.

My daughter is 23 years old and currently attends a post-secondary program, RISE, at Judson University in Elgin, Illinois. This is her second year in the program and we have seen great gains both academically and socially since enrolling at Judson. She was born with Down Syndrome. In spite of her diagnosis, we have always advocated for inclusion and she spent the majority of her public education in mainstream classes. Her goal was to further her education and receive a college experience.

She was recently pulled from the PUNS list and approved for Home Based Services. I had hoped that the funding for these services could include financial support for her tuition, but was informed that was not currently an option. I would respectfully request the MAC Board take into consideration the changes in education opportunities for individuals with disabilities and consider approving medicaid waiver funding for postsecondary services whether it be in a university such as my daughter attends, a trade school or community college. With the passage of HB 3950, community colleges and other entities are directed to provide access to higher education for students with disabilities.

However, the lack of scholarships and other financial aide available to this population make it difficult for them to take advantage of these new opportunities. I believe with the changing landscape of education and employment for individuals with disabilities, the Board needs to look at other options for those dollars to be used. Investing in continuing education with the goal of a more independent, self-directed future would certainly be a worthwhile cause.

As my daughter completes the two year certificate program this year, the University recently announced plans to expand RISE to a 4-year program with more paid work related opportunities and assisted living skills. It is an exciting chance for my daughter to continue her dream of semi independence and competitive employment. Unfortunately when she was young there were no programs like this available and we were not encouraged to save for college. I have been utilizing my retirement savings to invest in my daughter. I'm sure many other parents of disabiled children are in the same predicament. It would be a wonderful advancement if the Medicaid Waiver funding could be used in this manner.

Thank you for taking time to read my request. I appreciate the work your committee does to improve the life of my daughter and so many others.

I would be happy to speak more about this request. Feel free to reach out with any questions or comments.

With graditude,
Gayle Griffin
[redacted]

[redacted]

From: Jonathan Neidorf [redacted]>
Sent: Tuesday, January 4, 2022 4:44 PM
To: Moroney, Gabriela M.
Subject: [External] MAC CI Written Comment

Categories: CI

Dear Ms. Moroney,

Please share the following testimony with the subcommittee. Thank you.

I am a researcher and my work focuses on community integration of people with intellectual/developmental disabilities (IDD). Previously, I was a Direct Support Professional (DSP), job developer, and administrative staff in two disability service providers in the greater Chicago area. I have been exposed to many different philosophies on how people with IDD ought to live. In my professional opinion, based on personal and scientific observation, people with IDD deserve to live both as independently and integrated in the community as possible, and an extensive HCBS system is crucial to providing such opportunities.

Illinois must increase its investment, financially and philosophically, in HCBS, not large institutions. Intermediate care facilities are not just inefficient and costly. The people living there are denied their rights to privacy, autonomy, and independence, solely on the basis of their disability. I have seen time and again the inspiring changes in people's qualities of life as they are given more opportunities to live independently. This is most obvious in moving from large state-operated developmental facilities to smaller community-integrated homes. Illinois's priorities to respect people with IDD and improve their quality of life must include strengthening HCBS financially and offering more people the opportunity to live in integrated settings.

Thank you,

--
Jonathan Neidorf
he/him/his
C: [redacted]
[redacted]

Moroney, Gabriela M.

From:	Joan Martin <[redacted]>
Sent:	Tuesday, January 4, 2022 4:45 PM
To:	Moroney, Gabriela M.
Subject:	[External] MAC CI Written Comment
Categories:	CI

Hello-
My 2 adult children have I/DD and live fully engaged lives that were created with them through their education process in preparation for Adult Living. ISBE encourages partnerships with family and community. How is this philosophy described in the IDHS/DDD?

My adult children live in an Individually Owned CILA in the Northern Suburbs of Chicago.

Since the process of transitioning to CILA services began in their lives over 10 years ago we often find it shocking how much parents are asked to be "fill in support staff" instead of "parents." Yet, they are not viewed as team members or welcomed into the processes of supports and services.

Providers in general, find it financially and physically challenging to provide their clients with access to an inclusive community with individualized jobs and activities. Home numbers are still to large and there is not funding to think about how to give access to an independent or individualized life.

Case Management lacks in hours and qualified personnel to provide Person Centered services and supports.
How does the division provide required Person Centered Living Training?
Are these tenants of PCL left to the discrepancy of the provider?
Is there required training and oversight from top down personnel?

Case Management is needed to:
Grow Supported Decision Makers (Not just removing guardianship)
Teach Financial Wellness so clients can learn how to be skilled decision makers (for their personal safety and enjoyment)
Provide Quality Healthcare Oversight and Management by Nurses
Create Communications with Employers to support ongoing integrated/customized employment
Search Social Opportunities to explore truly integrated lives in established community sites. (Clubs, Library programs, Rec Centers, Social Groups in areas of interest.)

There is a concern that QUALITY OF LIFE is too subjective in the process of measuring provider's competencies. BALC does not take these important factors into consideration when measuring a providers performance.

Thank you for the opportunity to share our concerns in these areas for the security of Long Term Supports and Services. One of my Adult Children has intense support needs and there seems to be a lack of awareness for this low incidence population, in regards to the array of supports and services needed to live a full and healthy life. If not now… how can we know that without our presence in the inevitable future, that our Adult Children will be provided for appropriately?

Has the division had discussion regarding specialized care provided as supports to the provider/individuals for this population of clients.

Thank you-
Joan Martin
Good Life Designers, LLC
[redacted]

From: Therese Bandstra <[redacted]>
Sent: Tuesday, January 4, 2022 4:48 PM
To: Moroney, Gabriela M.
Subject: [External] MAC CI Public Comment

Categories: CI

Dear Gabriela,

I received an email from the Arc of Illinois about IDHFS seeking comment from the public about unmet needs for improving community integration for individuals with disabilities.

I have a 34-year-old daughter who is mentally disabled. She and 3 other compatible women would like to live in a 4-person CILA in our town of Ottawa, IL where they have jobs. We are looking to begin a new CILA, a small one, in which there is a limited amount of people living in the house. We hope to have a small setting to limit exposure to Covid; we also hope for a program that allows them to go to their jobs daily and NOT go to a day program where they have contact with a large group and thus more exposure to Covid.

I am not sure that my local agency has the vision for this kind of setting. With Covid appearing to be an ongoing concern, smaller groups of disabled individuals living together and being allowed to continue their lives safely with freedom is an unmet need.

I would appreciate any direction you can give me on this.

Thank you,
Therese Bandstra

AgeOptions

Connecting Older Adults with Community-based Resources and Options

Jan 4, 2021

Members of the HFS Medicaid Advisory Committee -Community Integration Subcommittee,

Thank you for the opportunity to provide public written comment in regards to how Illinois Medicaid beneficiaries are accessing HCBS waiver services. Avisery by AgeOptions is a statewide program that provides training and technical assistance to professionals who assist older adults and people with disabilities navigate Medicare and Medicaid and also advocates for increased access to affordable health coverage.

Avisery interacts with professionals who counsel potential beneficiaries of HCBS waiver services. Avisery canvassed the professionals we work with and asked them the 4 specific questions about HCBS services raised by this committee. We have categorized their responses into the following themes: barriers to Medicaid enrollment; workforce-related service delays; under-utilization of Home Delivered Meal (HDM) services; transitions from facilities to community living; lack of support for caregivers; and the need to think creatively about additional services that would prevent/prolong the need institutional care.

Barriers to Medicaid Enrollment

Establishing Medicaid eligibility is the initial step in qualifying for HCBS services; therefore, barriers to Medicaid enrollment can be the first obstacle to accessing these needed services. Some of these barriers include:

- Professionals report that many clients are unaware that these services even exist, which in and of itself is a significant barrier to obtaining service.
- Many potential beneficiaries struggle to apply online because they cannot successfully verify their identity and are not aware of the potential solutions for this problem. Reductions in DHS local office staffing due to COVID exacerbates these application-related problems.
- Although Illinois' Health Benefits for Immigrant Seniors program is not a Medicaid program, it has provided critically needed access to health services for Illinois residents who do not otherwise qualify for Medicaid. Exclusion of HCBS services from this program leaves many immigrant older adults without access to services that would allow them to remain in community settings.

Workforce-Related Delays in Accessing Services

Professionals report a rising need for HCBS services among persons over 60 and those with intellectual/developmental disabilities, particularly those transitioning out of the educational system. Yet even with the current level of demand, the system is not running smoothly. Many of the pressing concerns about HCBS Waiver services raised by the professionals we asked are issues surrounding workforce capacity, including the following:

- Avisery members report to us that Care Coordinators at Care Coordination Units (CCUs) for older adults have large caseloads often across large geographic areas; that make it difficult to complete assessments in a timely way. In addition, current rates paid to the CCUs do not adequately cover the costs of completing assessments. As a result of being under-resourced and overworked, CCU personnel have a high rate of turnover and difficulty recruiting staff.
- Professionals additionally report that eligibility evaluations for the Persons with Disability waiver have also been delayed due to Covid-19 remote working protocols.
- Once a beneficiary is approved for services, the development of a specific care plan for that individual may also not occur in a timely way; our respondents cited access barriers due to the delays in the MCOs process of creating care plans for waiver services.
- Waiver beneficiaries can experience further obstacles to receiving services after the care plan is in place. Many home care providers are experiencing staff shortages and do not have the capacity to admit new clients. In particular, there are not enough vaccinated homemaker staff. Waiting lists are common, and these problems are additionally exacerbated in rural counties and other outlying areas.

While there is a plan to address workforce issues in the Build Back Better plan on a federal level, such as funding to invest in the workforce, Illinois should be working on plan to address these issues on a state level. The professionals we heard from made the following suggestions to address the workforce problems they cited:

- Increase rates for CCUs so they can hire more Care Coordinators.
- Make the eligibility assessment process less cumbersome.
- Allow undocumented workers to be employed as "support workers" if they meet other eligibility requirements.
- Allow Personal Support Workers to provide assistance for those with higher support needs outside the home (e.g., to attend CDS programs, or in employment settings).

Underutilization of Home Delivered Meal (HDM) services

Participants in HCBS waivers that do not cover home delivered meals are not being fully served in regards to accessing Older Americans Act Title IIIC home delivered meals. AgeOptions tracks referrals from MCOs to our home delivered meal program providers, and the numbers are well below the need. We suspect that if the MCOs aren't appropriately referring participants to meals, that they likely aren't referring them to other services either.

- MCO care coordinators do not seem aware of the availability of OAA-funded meals, despite extensive attempts by the Area Agencies on Aging to train them and facilitate referrals. Beyond temporary use of meals after a hospital stay, MCOS are not referring waiver recipients who are eligible for OAA-funded meals to HDM providers for ongoing services, even though HDM services are critical to helping these beneficiaries remain in the community setting.
- When MCO members are up for their annual reassessments for home delivered meals, meal providers have a very difficult time contacting the member's MCO care coordinator. Meal site managers report that this is an ongoing issue.

Suggested changes to improve access to Home Delivered Meals (HDMs) for waiver recipients include:

- State agencies should include in their MCO contract expectations that the MCOs will connect HCBS waiver recipients with home delivered meals. The agencies should monitor MCO performance on HDM referrals.
- MCO care coordinators should continue receiving training on HDM and how to find the correct meal provider for their member. MCOs should encourage their care managers to connect members to HDM services.
- HDM providers need a way to be able to quickly identify and contact the correct care coordinator for their MCO managed client.

Transitions to Community Living

Individuals who are eligible for waiver services encounter a number of logistical issues when they are transitioning from a long-term care facility back into the community.

- Individuals transitioning out of a nursing home placement often must hire a caregiver on their own; yet many of them had been in an institutional setting due to having limited social support. There is no system in place to help these individuals easily locate workers.
- MCO care plans limit the level of services for transitioning individuals, but these recipients need more significant support during this period of time, and potentially beyond, to remain in the community successfully. The MCO's also need to better prioritize these individuals to speed up the transition process (e.g., attending interdisciplinary team meetings with the facility, ordering durable medical equipment, etc.). The MCO care coordinators can be difficult to reach and have high turnover.
- When individuals transition back to the community, they must have a physical address in order to access services, but landlords may want to know first if HCBS services will be in place before renting them the apartment.
- There is a delay between the DHS system and community-based providers system when it comes to the providers billing. The DHS system will say the individual is transitioned to the community and the providers will not have this information.

Lack of Caregiver Support:

Avisery would like to draw attention to the critical role unpaid caregivers play in allowing HCBS waiver recipients to remain in their home. Current HCBS waivers do not currently include services that benefit and support these caregivers sufficiently. We recommend the following:

- Mandating administration of the TCARE assessment to primary caregivers of Person who are Elderly 1915 c waiver participants. It is documented that the TCARE assessment, the one-on-one counseling provided to caregivers and linkages to resources delays institutionalization.
- Services that allow unpaid caregivers to remain in the workforce by increasing services to the waiver recipient. Current care plan maximums do not allow such coverage in the aging services.
- The inclusion of a respite care benefit that provides waiver participants the opportunity to utilize short stays in an institutional setting or a 24-hour in-home short-term benefit would also relieve caregiver stress and burn-out by enabling the caregiver time away from their

direct care responsibilities. This respite benefit would not terminate their current plan of care, but rather suspend the services during the period when the respite benefit is used.

Other Services to Prevent/Delay of Institutional Care

The exploration of other benefits that could delay or prevent long-term institutionalization is needed. The HCBS waivers by design are an alternative to nursing home placement. In general, AgeOptions encourages Healthcare and Family Services and all of its sister state agencies that offer home and community-based waivers to explore creative ways to work on the front-door to nursing home placement. As one such example: if a temporary housing assistance benefit were offered during a person's nursing home stay, reduce the number of long-term placements and promote the state's intensive efforts at de-institutionalization under the Consent Decrees. Additionally, non-standard DME could be included-such as “reachers”/”grabbers,” toilet seat risers, and covering both wheelchair AND walker/cane if indicated and non-medical transportation services would also be beneficial. Similar “outside-the-box" thinking could address the reasons why people become unable to remain in their homes or unable to leave an institution.

AgeOptions appreciates the opportunity to provide you with our thoughts regarding the HCBS waivers.

Sincerely,

Diane Slezak, CEO

From: Mary Ann Ogilvie <[redacted]>
Sent: Tuesday, January 4, 2022 5:09 PM
To: Moroney, Gabriela M.
Subject: [External] MAC CI Written Comment in the Subject line

Categories: CI

Good afternoon, Ms. Moroney,

I am writing to provide comments for the MAC Integration Subcommittee that meets tomorrow. My comments are based on my personal experience with HCBS services for my 24-year old son David. Our agency is Clearbrook.

1. The agency has not been able to find another PSW. David has one PSW who often cancels his weekly 3-hour visit.
2. In the past, my husband and I have spoken with the CEO of Clearbrook and discussed the idea of our providing a home for Clearbrook to use as a CILA so our son has a good and healthy place to live. We would consider giving them the home. We were told that, although this is a generous offer, Clearbrook would not use the home as a CILA, but rather sell it and use the funds for expenses. They need money and staffing more than they need a structure.

Thank you.
MaryAnn Ogilvie
Sent from [redacted] for Windows

EQUIP FOR EQUALITY

Advancing the human and civil rights of people with disabilities

SELF-ADVOCACY ASSISTANCE ★ LEGAL SERVICES ★ DISABILITY RIGHTS EDUCATION ★ PUBLIC POLICY ADVOCACY ★ ABUSE INVESTIGATIONS

January 5, 2022

Gabriela Moroney
Illinois Department of Healthcare and Family Services
Medicaid Advisory Committee
Community Integration Subcommittee
Via Email Only: Gabriela.M.Moroney@illinois.gov

Re: Comments on Medicaid Waivers and Community Integration

Dear Ms. Moroney:

Thank you for the opportunity to provide comments on the use of Home and Community Based Services (HCBS) Medicaid Waiver funding to expand opportunities for Illinois residents to be integrated into their communities. We welcome the Pritzker administration's efforts to move Illinois away from its antiquated service system and its unenviable spot as one of the most segregated states in the country. Illinois desperately needs to expand its HCBS options, as many are being left behind, spending decades—even lifetimes—in institutions or living in the community without needed services.

Before addressing individual waivers, we do have some comments that apply more globally. To address Illinois' heavy reliance on institutions, Illinois should provide community-based services with reasonable promptness as required by Medicaid; remove (or, at minimum, expand) service caps; remove (or, at minimum, increase) service cost maximums; provide waiver participants the requisite hours of service, rather than providing them with a dollar amount; add intensive case management as a service for all waiver participants; and educate the public on the benefits and availability of waiver services. Additionally, all Medicaid waivers should have a wide range of services available to participants, so they don't need to navigate through confusing state plan services, prior authorizations, and service limitations.

<u>Institutionalized adults with developmental disabilities (DD)</u>
More than 6,000 people with DD remain in Illinois' massive array of public and private DD institutions—SODCs, ICF-DDs, and MC-DDs. This is in stark contrast to most states, many of which have *no* residents with DD in institutions. Most people with DD who are institutionalized in Illinois do not even know that they have a right under the Americans with Disabilities Act (ADA) and under Medicaid to live in the community. Illinois' failure to provide this information is itself in violation of the ADA and Medicaid, both of which require states to educate institutionalized people about their option to live in the community.

The Independent, federally mandated Protection & Advocacy System for the state of Illinois

Mark P. Rotatori, Board Chairperson Zena Naiditch, President & CEO

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The hardships of living in an institution and the benefits of living in the community have been extensively documented in professional literature and in caselaw, including the most well-known community integration case, *Olmstead v. L.C.* The COVID-19 pandemic has only increased the hardships of institutionalization, preventing residents from seeing friends and family and exposing residents to rates of disease and death that are higher than those in the community.

Note also that, for the first time in years, Illinois' SODC census has increased from the previous year. This is in large part due to the failure of Illinois' community system to accommodate the needs of people with developmental disabilities who have additional disabilities, such as diabetes, respiratory disease, physical disabilities, and mental illness. As a result, people who could and should be served in the community are instead sent to SODCs for "short-term" stays, most of which end up being years' long.

Sadly, even people who live in Illinois' community system often experience a degree of institutionalization. Illinois, in contrast to most states, allows its group homes (CILAs) to be as large as eight people, and a majority of our CILAs are that size. Research supports that smaller group homes—two or three people, and certainly no larger than four people—promote individual choice and a higher quality of life. Additionally, poor regulation of these larger homes results in unacceptable restrictions, including restrictions on who can visit and when a resident can leave the home.

To help remedy this unconscionable reliance on institutions, HFS and DHS need to:

- provide annual education to people who live in DD institutions of their right to live in the community—education that is appropriate to the learning styles of the residents and includes multiple modalities, such as discussion, films, and visits to community settings;
- provide community-based services with reasonable promptness and at a reasonable pace for people who want to move out of institutions;
- ensure that the community system has services to meet the needs of people who have disabilities in addition to DD;
- ensure that the community system provides accommodations (such as sign language interpreters), as required by the ADA and Section 504 of the Rehabilitation Act;
- limit CILA size to four people;
- increase the number of short-term stabilization homes to prevent unnecessary institutionalization in SODCs; and
- increase the number of CILA providers.

Service caps on the Children and Young Adults with Developmental Disabilities Support Waiver

Children and young adults (collectively, youth) with developmental disabilities who are on the Support Waiver face a financial cap on services that often prevents them from getting the services they need in the family home. As a result, they are pushed into residential settings or languish in hospitals, both of which cost the State far more than would the provision of appropriate services. It is not unusual for HFS to pay over $100,000 per year for a youth to be housed in a residential setting, but the Waiver, which is supposed to prevent institutionalization, provides only 2x SSI per month in home-based services. This is contrary to the opinions of experts in the field, who have concluded that most youth do better in the home, provided they have appropriate services. This does not even take into account the horrific treatment that many youth experience in residential settings, including sexual, psychological, and physical abuse by staff and by other residents. This cap must be removed.

Another issue with the Support Waiver is that it is not available to youth until they are in crisis. The purpose of the Support Waiver should be to allow youth to be successful at home, not to try to repair things when they have fallen apart. By that time, parents may be so exhausted that they feel that they have no option but to send their child away. And even when youth meet the crisis standard, they often are forced to wait months for services. This is inexplicable, given that information we received from a FOIA request last year showed that nearly one-third of Support Waiver slots were not being used.

To help remedy the deficiencies in the Support Waiver and avert costly and often detrimental residential placement, DHS and HFS should:

- eliminate waiting lists for services and make services available *before* youth get into crisis;
- remove all caps, as Medicaid youth under 21 are entitled to *all medically necessary services*; and
- make the service package more comprehensive by adding intermittent nursing, intensive case management, mobile crisis services, SST, therapies, wrap around services, and therapeutic mentoring.

Elderly Waiver

The Elderly Waiver is inferior to the Persons with Disabilities Waiver in several important respects. Participants in the Persons with Disabilities Waiver can choose between hiring personal assistants or using agency-based homemaker services. In contrast, participants in the Elderly Waiver are not allowed to hire personal assistants; they must use homemaker services. As a result, participants in the Elderly Waiver have less control over who provides them care. Moreover, each hour of care is more costly, as the agency charges for its services. Thus, the amount awarded by the State purchases fewer hours under the Elderly Waiver than it does under the Persons with Disabilities Waiver. For example, if a person received $1,000 per month, they would receive about 67 personal assistant hours (using a rate of $15 per hour) but only 50 homemaker hours (using a rate of $20 per hour).

Equally disturbing is that many homemaker agencies don't allow their employees to do tasks that are essential to Elderly Waiver participants, such as operating Hoyer lifts or catheterizing. Facing limited hours from employees who are limited in what tasks they are allowed to perform, many elderly people unnecessarily end up in nursing homes. In contrast, participants in the Persons with Disabilities Waiver can hire people who are willing and able to do whatever the participant needs, including operating Hoyer lifts and catheterizing. Too many individuals are stuck in nursing homes simply because they cannot transfer independently.

Another difference is in the service array. The Persons with Disabilities Waiver offers a wide array of services, including home modifications, nursing, therapies, and assistive technology. The Elderly Waiver has an extremely limited array of services.

Another deficiency in the Elderly Waiver is that the service cost maximum (SCM) assigned to DON scores is often much lower than actual nursing facility costs. According to information received from a recent FOIA request, the average DON score under the Elderly Waiver is 50 with an average authorization amount of $1,204 per month. According to the HFS nursing facility rate sheet, it appears the average nursing facility cost per month is $5,200. The State should be willing to pay up to the nursing home cost to allow the person to move out of the nursing home. For example, under our current system, the State might be paying $5,000 monthly for a person to stay in a nursing home. Yet, under the Elderly Waiver, the SCM might be capped at $1,500, which would not purchase sufficient services to allow the person to move out, as the person needs $3,000 worth of services to be successful in the community. Thus, the outcome is bad for the person—they are forced to stay in the nursing home contrary to their wishes—and bad for the State, which is paying $2,000 per month more than it would cost for the person to live in the community.

To help remedy the deficiencies in the Elderly Waiver, Department on Aging and HFS should:

- allow participants to hire personal assistants if they wish to;
- if participants use agency homemaker services, increase the amount of money they receive so they do not lose hours by virtue of their reliance on homemakers rather than personal assistants;
- require homemaker agencies to expand service array and at least perform the same services that personal assistants perform, including operating Hoyer lifts and performing catheterization;
- expand the service array in the Elderly Waiver so that it is comparable to the service array in the Persons with Disabilities Waiver, including nursing, assistive technology, and home modification;
- allow SCMs to go up to the current nursing home rate and allow exceptions to the SCM (which is currently only allowed under the Persons with Disabilities Waiver) or remove the SCM altogether.

Persons with Disabilities Waiver

Some participants are not able to hire their own personal assistants and thus choose to use homemaker services; they should not be penalized for doing so by getting fewer hours of services due to the higher homemaker rates. As discussed in connection with the Elderly Waiver, participants should be approved for service hours, not approved for an amount of money. They should receive the same number of hours of care whether they hire a personal assistant or a homemaker through an agency. For example, a person who has been approved for 16 hours per day of personal assistant services should not receive only 10 hours per day if they choose or require the use of a homemaker agency. Also, as discussed in connection with the Elderly Waiver, homemakers should be required to operate Hoyer lifts and catheterize when needed. Too many individuals are stuck in nursing homes simply because they cannot transfer independently.

As with the Elderly Waiver, SCMs under the Persons with Disabilities Waiver are often inadequate to meet the needs of individuals and are far lower than comparable nursing home costs. As a result, the State is compelled to pay nursing home rates, even when providing robust home care would be less expensive. This is especially concerning during a global pandemic when institutionalization could cost someone their life.

Participants should not be disadvantaged in any way due to their participation in managed care. Currently, people who do not participate in managed care are allowed to get more hours than the SCM dictates if there is medical necessity. In contrast, we have seen MCOs refuse to exceed the SCM, even where there is medical necessity.

Also, DRS should, after determining an individual to be eligible for Waiver services, commit to maintaining at least the same level of services absent a specific finding in the annual redetermination that the individual's condition and level of need have become less acute. As most Waiver participants have chronic conditions that do not improve and only grow more acute over time, only in very rare instances should DRS reduce a participant's services from year to year.

To help remedy the deficiencies in the Persons with Disabilities Waiver, DHS and HFS should:

- if participants use agency homemaker services, increase the amount of money they receive so they do not lose hours by virtue of their reliance on homemakers rather than personal assistants;
- require homemaker agencies to perform the same services that personal assistants perform, including using a Hoyer lift and performing catheterization;
- allow SCMs to go up to the nursing home rate;
- require MCOs to administer the Waiver in the same fashion that the State administers it, including allowing SCMs to be exceeded when medically necessary; and
- commit to maintaining services from year to year, absent a specific finding in the annual determination that a Waiver participant's condition and level of need has become less acute.

Thank you for this opportunity to share our thoughts with the Community Integration Subcommittee.

Sincerely,

Laura J. Miller

Laura J. Miller
Managing Attorney
Civil Rights Team

Moroney, Gabriela M.

From: Gibson, Jo <[redacted]>
Sent: Wednesday, January 5, 2022 4:11 PM
To: Moroney, Gabriela M.
Subject: [External] MAC CI Written Comment

Categories: CI

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?

Barriers to allowing **choice of living arrangement** to participants.

A lack of providers, especially those providers wanting/willing to provide Intermittent CILA only services. The DRAFT – Intermittent CILA (ICILA) Services and Supports Clarification of Program Scope and Billing https://www.dhs.state.il.us/page.aspx?item=138217 scope limits appropriate services and supports necessary for *less than highly funtioning* IDD individuals. In addition, Administrative costs are embedded in each billable service which takes away from hours for direct support.

• Where and with which populations is demand for home and community-based services rising?

Less than highly functioning IDD individuals who do not want 24/7 CILA yet would be able to function in Intermittant CILA situations with adequate support.

• 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?

Lack of provider services.

Lack of affordable housing.

Lack of DSPs

Families seem to be 'on their own' to find an appropriate provider.

• What are some ideas for expanding access to Illinois Medicaid home and community-based services?

Appropriately FUND!

Respectively,

Jo Gibson, parent/guardian of IDD individual and Waiver Participant

To whom it may concern,

Thank you for allowing me to be a voice for people with mental illness who need much more care and support than the current system offers. After working almost thirty years at the Elgin Mental Health Center, I have witnessed countless tragedies that could have been avoided had more people understood mental illness, knew when and where to access care and then felt comfortable enough to say they had sick brain health.

I have witness numerous discharges into the community where twenty- or thirty-year-old individuals are delivered to nursing homes. They are promised a bus pass, a transition into the new area (which does not include health clubs, libraries, recreational facilities or any local facility which can maintain or facilitate their wellness), a monthly allowance, and an agency that will help them "move on" living back into the community.

These things are required to complete the mission for people to achieve the recovery promised to them should they faithfully fulfill their obligations for 8, or 15, or 25 years at the mental health center. However, for an individual discharged to a nursing home, there is little hope that any of this will happen.

Individuals in their thirties are discharged to a nursing home with no adequate funding in place. Half a year goes by and no one at the nursing home has even had time to fill out the application needed for a mental health disability. Lack of funding creates no access to a monthly allowance ($2 a day; while the nursing home keeps the rest and then bills Medicaid any inordinate amount of money per month for care), a free bus pass, or to qualify for any agency to interact with them. For a person to spend so many years at a state facility to be fully recovered and then left unequipped in nursing homes is unacceptable.

People living with mental illness need an advocate. Someone who knows them, someone they trust. A person who is part of their discharge plan. This advocate would be assertive and supportive in seeking the things they need, for if the discharged person is too proactive in trying to rebuild their lives, this is sometimes viewed in a negative, symptomatic way.

I am asking the committee today to please take care and compassion in making decisions when people with mental illness are trying so hard to stay well in a system set up for them to fail. I ask you to imagine yourself living in an institutionalized setting waiting, hoping, praying for someone to advocate for you; someone to help navigate the system and remind you everyday why waiting is the only thing you must do because in time (if you don't get sick again during this process) you can maybe live to your fullest potential.

Thank you for your time and consideration.

Warm regards,
Becky Ogrodny

I'm Kathy Weiman and I'm here today representing the Illinois Council of Care Coordination Units. The more than 35 Care Coordination Units, working on behalf of the Illinois Department on Aging, are present in every community in Illinois providing case management and linkage to HCBS through the Community Care Program as well as connecting to available resources in each community.

In this role, we have been working parallel to the Managed Care Organizations with the rollover of many older adults who are on Medicaid to the MCO's since 2017. As such, we directly encounter barriers to care for individuals served by the MCO's when we connect with them through an annual assessment or when they contact us for help.

Last month, we reached out to the Care Coordination Units and asked for them to share situations or examples of challenges they have encountered with accessing MCO assistance. Within a short two weeks, we received more than 75 examples of barriers to access to care for Illinois' older adults.

This list is indicative of the ongoing challenges we have dealt with since 2017. More than half of the cases involve older adults not being able to contact the MCO or contact was made and they have received no response. These include situations where a Care Coordinator from the Care Coordination Unit has contacted the MCO and received no response. The other half involved

-delayed, or very late responses to emergent needs,

-required assistance from the Care Coordination Unit to find the right contact

-the MCO terminating services without any explanation,

-the MCO redirecting back to the Care Coordination Unit to follow up in cases that the MCO has responsibility for.

In one case, a Care Coordinator contacted the MCO to share a high risk home with hoarding, bed bugs, mice and general filth. The participant was unbathed, wearing dirty incontinence products. When the Care Coordinator got ahold of the MCO contact, she stated she was "aware the house was in bad condition three months ago but spoke to the participant by phone and did not conduct a face to face visit because they don't do face to face visits." The Care Coordinator pulled together community resources to provide mental health support, ongoing case management, intervention with the bed bugs and mice and coordinated services with a daughter who has a disability through the Department of Rehab services.

In another situation, the Care Coordinator went out to do the annual assessment. The participant was outside on the porch because she had no air conditioning or fans and half of the home's roof was collapsed. The participant shared she had tried repeatedly to contact her MCO but could never get ahold of anyone. The Care Coordinator mailed the scenario to the MCO, again, no response. In this situation, the Care Coordination Unit used their own emergency funds to purchase fans and a stand along air conditions. They are working with Rural Development in the area to help fix the home.

A Care Coordination Unit received a call from the local homemaker agency regarding a participant who was having to move out of her home due to toxic black mold. They reported they had called the MCO several times but never got a response. The CCU is now pursuing use of Title III funds and possible emergency funds to get rid of the mold.

A participant was found deceased in her home and had been for several days. She had been with an MCO since July, 2021 and in and out of the hospital since July. No contact was made by the MCO and the participant was unable to reach the MCO. No one provided in face to face well-being checks.

During an annual home assessment visit, Participant reported having a broken electric wheelchair. The client has polio and is now bedbound because of the wheelcahri being broken. MCO is aware but have not communicated nor taken steps to resolve the issue.

And yes, the list goes on and on.

Separate from Managed Care challenges to accessing appropriate HCBS for older adults, the Care Coordination Units also are seeing a large barrier related to lack of homemakers. We frequently set up a care plan for an older adult to remain safe and healthy in their home, but have difficulty finding a homemaker agency able to staff these individuals.

As well, the Medicaid Estate Recovery requirement remains a barrier as many older adults do not want to sign over their home to the state in order to be eligible for services.

Respectfully,

Kathy Weiman, CEO
Alternatives (for the Older Adult, Inc.)

Presenting as Vice-chair, Illinois Council of Care Coordination Units

My name is Kira Meskin and I serve as a Community Reintegration Advocate at Progress Center for Independent Living for people residing in nursing homes and long-term care (LTC) facilities. Also during the pandemic, I have been doing a lot of emergency response work, particularly for people utilizing Home and Community Based Services (HCBS).

To highlight some of the barriers my consumers and friends have been dealing with:

- Hiring Personal Assistants: People have been facing significant difficulties and delays in hiring PAs, especially when it comes to getting someone to work evening/weekend hours. If you are a person who relies on PAs to help transfer you out of bed, not having this assistance is literally a matter of life or death.
- Homemaker agencies: There has been considerable turnover, which creates significant disruption in the quality of care they receive.
- At this time, there are people ages 60 and older who are presently stuck in institutions against their choice and are not being "allowed" to transition to the community, because the Dept. of Aging's HCBS don't meet their needs. This ongoing, systemic issue undermines both the Supreme Court Olmstead Decision and our state's consent decrees, which is a huge concern.
- There is a growing need for services under the Persons who are Elderly waiver; however, unless a person is utilizing the Brain Injury or HIV/AIDs waivers through Dept. of Human Services' Div. of Rehab Services (DHS/DRS), it seems particularly backwards that the amount and types of services are more limited as people age.

Aging in place is a widely known healthcare trend and best practice, which inherently relates to expanding our state's HCBS. On that note:

- We need to incentivize PA positions by increasing their pay and offering additional benefits, especially during a pandemic where it's hard enough to hire people to do frontline direct care work. Paying PAs $15.50/hour doesn't cut it (based on DHS/DRS' current pay rate). Also, a majority of PAs are people of color and immigrants, which further exacerbates the health disparities we all know exist. This is not a new issue and has been ongoing for years. Something finally needs to change.
- Expanding home modification services not only promotes one's safety, independence, and quality of life, it avoids people from having to go to the hospital. During the pandemic, what we know is that there has been an increase in hospital discharges to nursing homes and LTC facilities, which is the last place people should go when more than half of our state's Covid-related deaths have

been in congregate care settings. Also, to even transition out of a nursing home/LTC facility, it can take on average at least 1-1 ½ years.

- Dept. of Aging needs to expand their Community Care Program to include direct assistance with transferring in/out of bed (including the use of transfer devices), set-up and administration of medication, completing personal hygiene tasks related to toileting, diabetes management, feeding tube assistance, etc. It also needs to include an increase of hours more than only once a day, a few days a week, as well as assistance during the weekend.
- It is wonderful that Illinois' Front Door Diversion Program was established recently in July, and we also need to keep developing it. To my knowledge, this program focuses on diverting people who experience mental illness and have psychiatric needs; however, people with physical disabilities and who have intellectual and/or developmental disabilities (I/DD) also need to be prioritized so that way they are not placed in institutions to begin with.
- Access to information and technology are huge barriers for people with disabilities. As part of providing effective communication, it is best practice for state agencies and MCOs to utilize multiple means of communication. This means sending mail <u>and</u> making phone calls <u>and</u> sending texts messages <u>and</u> emails. It also means that information needs to be shared more than once, otherwise these efforts are mostly futile, especially when it comes to emergency response and recovery services.