

Cutting Services, Eliminating Independence: What Changes to the DON Score will Mean for Illinoisans

"I want to live my life in my way, in my own place, on my own time." -Frances

The Proposed Change and Implications

In an effort to reduce costs, Illinois Governor Bruce Rauner has proposed to increase the minimum eligibility threshold for the Determination of Need (DON) assessment. The DON is used to determine eligibility for long term services and supports provided through the State's Home Services Program (HSP) and the Community Care Program (CCP). The DON cut-off score, now at 29 points, would increase to 37 which means that new applicants must have greater health needs to qualify for services. Thousands of people would lose services.

The changes have been proposed in the form of amendments to the Home and Community Based Services 1915 (c) Waivers for Persons who are Elderly (CCP) and Persons with Disabilities (HSP). The proposed waiver renewals are written in a way that would prevent people dropped from HSP and CCP from qualifying for nursing home care. Both waivers seek "to modify waiver eligibility by increasing the minimum level of care threshold to match the nursing facility level." The eligibility levels for waiver programs and nursing facilities are expected to be aligned. With the current eligibility threshold for nursing home facilities at 29, the State would be required by its own language to also change the minimum level of care threshold for nursing homes to 37. To achieve this, Illinois would need to modify its Medicaid State Plan Amendment with the Centers for Medicare and Medicaid Services (CMS). While the State has not yet initiated a push to change the nursing home eligibility threshold, lawmakers have also not created plans for what to do with the pool of individuals who have a DON score below 37 and now live in a nursing home.

By the Numbers

Increasing the minimum eligibility threshold for the DON will have a profoundly detrimental impact: 10,000 persons with disabilities will lose their existing HSP services and 24,005 older adults will lose the services they currently receive under CCP. Applicants that would now be eligible for services would be denied with a new cut-off score as well.

The Impact on Illinoisans

Because these numbers fail to communicate the depth of the consequences, staff from Health & Disability Advocates (HDA), AgeOptions, AARP and Access Living have been testifying in front of State officials and collecting personal testimony from people who stand to lose services. These stories put a face to the numbers by emphasizing how the programs are effective; HSP and CCP empower Illinoisans to live independent, productive, and fulfilling lives.

What Services will be Lost?

HSP enables Illinoisans with disabilities to live independently in the community by providing personal assistance with a range of activities of daily living, such as getting out of bed and dressed, taking showers, meal preparation, and other household chores.

CCP allows older adults to age in place by providing adult day programs, emergency home response systems, and assistance with household tasks and activities of daily living that they cannot do independently.

The Benefit of Community Based Services: People Are Empowered to Live Productive Lives

Many people receiving HSP services lead active and productive lives. Support provided by personal assistants –help getting out of bed, taking a shower, getting dressed, cooking meals and completing household chores—allows people with disabilities to participate in and contribute to their communities. Many individuals shared stories of how they are able to work, contribute to their communities, and pursue higher education because of these State services.

The program helps me get ready to go to work every day. I am an advocacy coordinator for a Center for Independent Living. We cover all of the County. And I wouldn't be here today without my personal assistant. I would not be able to work at my job either.

Larry

My attendants arrive early in the morning at my house, before the sun comes up, to assist me in using the washroom, showering, and dressing. They help me brush my teeth, comb my hair, and wash my glasses and face, applying aloe cream to my overly dry skin. Then they help with a quick breakfast and/or cup of coffee so that I can catch a rush-hour train into the city for work before 8 a.m. I roll in my wheelchair the three blocks to the Metra stop. This all is difficult, but gives me a great deal of freedom, and indeed, my attendant services largely make it possible for me to be gainfully employed, and therefore, a taxpayer.

Tony

Without these services, I am not able to live independent daily life. I went to college, and these are the services that helped me get my two degrees. And without them I would be pretty much-- I wouldn't be able to go look for jobs, I wouldn't be able to be independent, and I'd be relying more on my parents.

Elaine

The Consequences of Losing Services: Well-Being Would Be Compromised

Older adults and people with disabilities are often able to manage their conditions because of their personal aid workers. HSP and CCP help people avoid costly emergency room visits through daily support that reinforces healthy habits, like medication management. Help with cooking, cleaning and laundry also minimizes the risk of falls, which can cause serious injuries that undermine well-being. Without home services and supports, health status will most certainly decline.

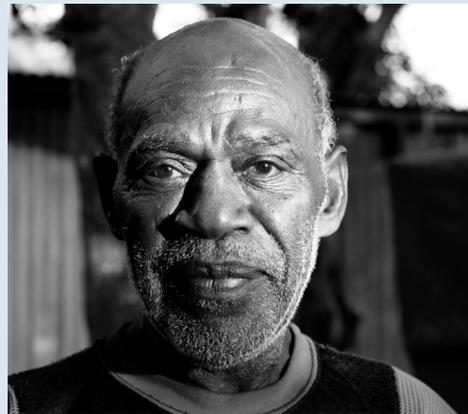
Another significant consequence could be eviction, as many people in HSP and CCP live in subsidized housing. Home workers complete chores that help people pass home inspections. Without home help, people could fail the inspections and get kicked out of their homes.

Without my home health care worker, I might forget to take my medicine. I have epilepsy. And if you forget to take your medicine or are under too much stress, like right now, I could have seizures. I've been paralyzed due to groupings of seizures. I still have left-side weakness because of the paralysis, not because of a stroke but because of groupings of seizures.

Jordan

She was in the hospital a lot before we had nursing. She was admitted-- she had two broken femur fractures. She had status epilepticus, which would require her to be hospitalized. She has not had any hospitalizations in the past four years, which I credit to nursing care being so helpful and wonderful.

Greg



When I don't have him [home aide] -- because I don't have him seven days a week. When I don't have him, he tries to get me set up for the weekend so that I can have a meal to microwave, because I can't stand on my feet for more than ten minutes. And if I try to, my back starts going off and hurting very badly. And so a lot of times he gets that stuff organized. He helps me to pay my bills. He helps me to go shopping, get moving, bathe and shower.

Teddy

More Consequences: Nursing Home Care Would Increase

Some people dropped from HSP and CCP will be transferred to nursing facilities. Although the State currently ties the DON cut-off for HCBS to the DON qualifying score for nursing home services. The 30-day emergency admission rule will enable those with DON scores below the new cut-off to be placed in nursing homes— at a greater cost to the State.

And I can't go to nursing home ever, never. I don't wanna go nursing home. I'll be alone. And also, numb. Because from chemo, my feets numb. I can't walk. I can't go to three steps. I go like this (indicating) when I go to upstairs or something.

Sarah

Some interviewed knew firsthand how undesirable nursing home life would be, having lived or worked in one previously. For these people, residing in a nursing home diminishes independence and autonomy.

When you're in a nursing home, you have to follow the rules, rules about when to wake up and when to eat, what to eat, when to take a shower. I mean, everyone knows you don't take a shower unless you could take it every single day. We took them, like, twice a week. I mean, I'm not kidding. I am an adult. I want to live my life in my way, in my own place, on my own time.

Frances

I used to work at a nursing home. You have no choices as a resident there: not what room you stay in, not what time you wake up, what your meals are, not the staff that assists you. The nurses can't leave the floor, so I used to take people outside. To me it doesn't seem fair, to have all this freedom taken from you, to not even be able to enjoy fresh air when you want it. I got to go home at the end of the day. My clients didn't. CCP and HSP were my number one referrals. There are no other programs like that, and those programs are the only reason that people are able to go back home, and they are the only thing keeping people from coming right back. I have no idea how I would stitch together discharge plans without these programs-it would just be a revolving door.

Sheila, Social Worker

The Proposed Changes and Nursing Facilities

CCP helps older adults maintain their independence, promotes their emotional well-being and gives family members peace of mind. People interviewed repeatedly stated that they did not want to live in a nursing home. It should be noted that if the State achieves its ultimate goal of increasing the cut-off score for both waiver programs and nursing facilities, people with a DON below 37 wouldn't even qualify for this unwanted option.

He's of pretty sound mind, but physically, he really can't do anything. He can't drive to doctors' appointments, shopping. Without these hours of home care, I don't know what would happen. He can't afford private assistance. And he does not want, again, want to go to a nursing home, as well. He's a World War II veteran. He's worked hard all his life. And I'm just not sure what would happen if he didn't get any assistance at all.

Elizabeth, daughter to Frank

I have a healthcare-giver four hours, five days a week. And what she does, she does the laundry for me, she does shopping, and she helps me with cooking. And she does the cleaning. Because I'm handi-capped, I'm in a wheelchair. I have neuropathy in both legs, and I need knee replacements on both knees. But I decided not to have the surgery because I'm 91 years old, and I'm afraid I wouldn't survive. So I'm using pain medication for the pain.

Alma

Family Can't Always Help

Implicit in the Governor's proposal is the assumption that family, friends and an already overburdened safety net will be available to compensate for the loss of State-funded care.

Testimony from HSP and CCP program users suggests this is dangerously presumptuous. Although family want and do provide support, they are often unable to do so at the required level. Also, many individuals do not have any family at all to provide support.

If I'm taken off the program, then I'm forcing my parents to either have to find me somewhere to live, like a nursing home, or we will have to pay out of pocket, which we really can't afford to do. So it's really going to impact me.

Danielle

My daughter has congenital muscular dystrophy. She's going to be 12 next month. She currently gets in-home nursing 56 hours a week. If they raise the DON score, she will no longer qualify, and she most likely will have to go to a home. I can't take care of her by myself at home.

Greg, Father of 11-year-old



I have a client who was admitted to the nursing home just recently because the homemaker, when they reduced her hours -- the son was working. He quit his job to take care of his mom. When they reduced the hours, about 24, 25 hours, he cannot afford that anymore. So he has to put his mom in a nursing home so he can go and find another job to make a living.

Maria, Executive Director, Social Support Agency

Increasing the Eligibility Level Would be Disastrous

The message is clear: CCP and HSP offer vital support to people with disabilities and older adults. The few individuals cited in this paper represent the faces of the collective 34,005 people who will suffer without access to vital home supports. Increasing the minimum eligibility threshold for the DON poses a direct threat to the livelihood of people with disabilities, older adults, and their families.