



The Ability Center

November 4, 2022

SUBMITTED VIA: <https://www.cms.gov/request-information-make-your-voice-heard>

RE: CMS-9912-N, RIN 0938-AU35

Medicaid Program; Temporary Increase in Federal Medical Assistance Percentage (FMAP) in Response to the COVID–19 Public Health Emergency (PHE)

Thank you for the opportunity to provide public comment on the Request for Information: *Make Your Voice Heard*. My name is Brittanie Maddox and I am a Disability Rights Advocate at The Ability Center of Greater Toledo. The Ability Center is a Center for Independent Living (CIL) serving seven counties in Northwest Ohio. Our mission is to make our community the most disability friendly in the nation by increasing independence for people with disabilities, discovering true passions, and changing the community's perception of disability.

Topic 1: Accessing Healthcare and Related Challenges

Dr. Martin Luther King once stated, "Of all the inequalities that exist, the injustice in health care is the most shocking and inhuman."¹ Access to receive quality health care is a basic civil right that has not dramatically increased since these words were spoken. Marginalized groups still encounter biases within the medical system and do not have equitable access to medical care as their peers. According to a 2022 report by the National Council on Disability², health disparities between people with disabilities and those without disabilities have not materially improved since their 2009 report, *The Current State of Health Care for People with Disabilities*. CMS must ensure that every person who receives public benefits, regardless of their marginalized identity, has equal and equitable access to health programs, procedures, and services.

CMS can streamline the prior authorization process and expand procedure coverage across all insurance providers.

As a disability organization, some of the more common barriers we hear to receiving healthcare services are lack of physical access, inaccessible diagnostic medical equipment, lack of adequate medicine and procedure coverage, and a cumbersome enrollment process. In a recent Ohio survey³ 23.14% of respondents stated they have difficulty getting insurance to cover all medical services needed. Once a medical professional deems a procedure, test, or medicine as necessary, the cumbersome process of prior authorization can impede medical care, especially if someone receives a denial. The basis for addressing the denial and review is time consuming and often interferes with important medical timelines. In a survey conducted by the American Medical Association, "nearly 90 percent of surveyed

¹ Newkirk, V. (2017, June 27). The Fight for Health Care Has Always Been About Civil Rights. *The Atlantic*. Retrieved from <https://www.theatlantic.com/politics/archive/2017/06/the-fight-for-health-care-is-really-all-about-civil-rights/531855/>

² National Council on Disability. (2022 August). *Health Equity Framework for People with Disabilities*. Retrieved from https://ncd.gov/sites/default/files/NCD_Health_Equity_Framework.pdf

³ The Ability Center of Greater Toledo, Ohio Statewide Disability Needs, Survey Report (2022).

physicians reported that prior authorization sometimes, often, or always delays access to care.”⁴ Insurance companies should not have the final say when and if a medical service or medication is appropriate or necessary nor should receiving medical services rely on this burdensome, bureaucratic process.

According to the CAQH 2019 Index, “the healthcare industry can save \$13.3 billion on administrative waste through automation of eight transactions including prior authorizations...”⁵ The process could be streamlined by moving prior authorization submissions electronically. The report further indicated that on average providers spend almost \$11 per transaction for a manual prior authorization and an electronic authorization is roughly \$1.88 per transaction. Electronic submissions could also speed up approval processes and decrease the amount of delays an individual might encounter.

A type of prior authorization that significantly impacts health care access and an individual’s well-being is step therapy. Step therapy is a process of medication trial that requires individuals to “fail” the preferred drug therapy before another medication could be tried. CMS released previous guidance stating that step therapy is cost effective and leads to better clinical decisions⁶. However, the burden and adverse effects are not felt by insurance companies or pharmacies, but the consumers. “Step therapy ranks the financial benefit of insurers and pharmacy benefit managers above the judgement of healthcare providers and poses unnecessary risks to patients’ health by delaying effective treatment.”⁷ The patient and their wellbeing should be priority when considering medication therapy.

Requiring patients to ‘fail’ a medication before trying a different one leads to potential long-term damage and increase in adverse health outcomes. For example, this practice is common for those with auto-immune conditions. An individual can see a flare-up of symptoms while waiting to ‘fail’ a medication not initially prescribed by their physician or while undergoing the prior authorization process that prohibits them from walking, working, and performing other activities of daily living. CMS can eliminate step therapy to ensure that patients have access to proper medical therapies.

CMS can submit guidance to health providers and systems on accessible diagnostic medical equipment.

Lack of accessible diagnostic medical equipment to receive yearly wellness exams, reproductive checks and screenings, weight measurements, as well as others, is a significant barrier to preventative medicine. One individual stated in our survey that, “Mammogram machines cannot accommodate wheelchair or med staff running the machines, med staff don’t know how to operate their OWN Hoyer lifts, dentists have no disability sensitivity training.” Preventative screenings are important to

⁴ Mills, R. (2017, January 25). Health care coalition calls for prior authorization reform. *American Medical Association*. Retrieved from <https://www.ama-assn.org/press-center/press-releases/health-care-coalition-calls-prior-authorization-reform>

⁵ Finnegan, J. (2020, January 22). Costs of prior authorizations increase for physician practices at an ‘alarming’ rate. *FIERCE Healthcare*. Retrieved from <https://www.fiercehealthcare.com/practices/costs-prior-authorizations-increase-for-physician-practices-at-alarming-rate#:~:text=The%20CAQH%20report%20said%20prior,an%20electronic%20transaction%20is%20%241.88.>

⁶ CMS Leadership. (2018, August 7). *Medicare Advantage Prior Authorization and Step Therapy for Part B Drugs*. Retrieved from <https://www.cms.gov/newsroom/fact-sheets/medicare-advantage-prior-authorization-and-step-therapy-part-b-drugs>

⁷ American College of Rheumatology. *Step Therapy: Instead of “Fail First,” Put Patients First*. Retrieved from <https://www.rheumatology.org/Portals/0/Files/ACR-Legislative-Brief-Step-Therapy.pdf>

maintaining a baseline level of care. Without proper access, many people with disabilities are unable to receive such screenings leading to an increased risk of disease and disability complication.

We hear a great deal how dental offices are inaccessible. Dental health and services are vital to holistic care and significantly impact the overall health of a person. Physical access is often a barrier for wheelchair and mobility users. For example, dental rooms are often narrow and small. Some individuals are unable to transfer from their wheelchair to a dental chair. If a person's wheelchair reclines, it would be feasible for them to stay in their chair during a dental appointment; however, the rooms are often too small to fit an additional chair. The United States Access Board has released guidance on accessible diagnostic medical equipment⁸. CMS could assist with its promotion and ensure that health care providers and systems are aware to increase access for people with disabilities.

Another barrier is the lack of Dentists who know how to interact with and treat their patients with disabilities. New York University created a new dental center aimed at treated patients with disabilities. This new center has a wheelchair recliner that enabled one individual to remain in her chair and titled back to receive proper dental care⁹. This center also works to ensure their graduates have the skills and knowledge to care for individuals with disabilities. Such services should be accessible throughout the country. CMS could partner with other dental schools and centers to increase access to dental services as well as expand billing options for dentists to be appropriately compensated for their services.

CMS can work with agencies to advise of up-to-date health care services and provide training to frontline staff.

Since the COVID-19 pandemic, the country experienced significant job turnover. There is little time to train and on-board new staff to keep up with the ongoing demand. Consequently, frontline staff are not prepared. We hear from consumers that there is little knowledge on the different services someone can be eligible for and often the person with a disability has a better understanding of what is offered. When someone is approved for public benefits, there is little education on the different health plans during open enrollment or those who are new to Medicare and Medicaid. People are often told to see which insurance plan has their doctor listed. CMS could partner with agencies to develop training on what are people's rights to receive services and the various options available.

Technology is another barrier to accessing healthcare depending on geographical location, access to technology, limited knowledge and/or ability to use technology, as well as lack of information in plain language and interpreter barriers. Researching various health plans often depends on the ability to navigate technology and know what plans are offered in an area. Health plan information should be communicated through an interpreter, Braille, plain language, and mailers in addition to website publication. Since people with disabilities have various forms of communication, CMS should ensure that communication from insurance providers meets the needs of the community.

⁸ U.S. Access Board. *Medical Diagnostic Equipment Accessibility Standards*. Retrieved from <https://www.access-board.gov/mde/>

⁹ Saint Louis, C. (2019, May 2). Saving the Teeth of Patients With Special Needs. *The New York Times*. Retrieved from <https://www.nytimes.com/2019/05/02/well/live/special-needs-dentist-nyu.html>

CMS should communicate through disability agencies and networks.

Disability agencies and networks are the community resource for information, services, and assistance. These groups have direct contact with people with disabilities and have formed a level of trust within their community. This network is best equipped to know how to communicate, and CMS should communicate updates, changes, and any pertinent information with these organizations. CMS could initially identify the key stakeholders in Ohio to discuss evolving health care rules, regulations, etc. as the information is distributed.

CMS could expand their policies and procedures to promote inclusion of diversity as standards of practice.

Marginalized communities encounter many attitudinal barriers within the health care system that impact the level and quality of care someone receives. People with disabilities often share experiences of bias, stereotypes, and discrimination by health care professionals. In a 2021 study by Lisa Iezzoni, et al., of the 714 physicians surveyed, 82.4% reported that people with disabilities have a worse quality of life than those without disabilities¹⁰. Receiving quality and timely care should not be determined by a person's disability. CMS could assist Universities, Colleges, and Trade Schools to increase the education of medical professionals on diversity, equity, accessibility, and inclusion. Educating these students early in their education helps to change the perception of disability. These students will feel more comfortable and knowledgeable about how to interact with their patients.

Topic 3: Advancing Health Equity

While it may be assumed that people with disabilities receive the majority of health care in the US, and thus, health equity for people with disabilities may be difficult to measure, disability is actually separate from health status.¹¹ People with disabilities are four times as likely to report their health as fair or poor than people with no disabilities.¹² In reality, there are “avoidable differences in health outcomes” between people with disabilities and people without disabilities due to social, economic, or environmental disadvantages, termed health disparities.¹³ In short, people with disabilities often receive inadequate health care due to social, environmental, and economic factors.

CMS has the ability to affect these disparities. Many people with disabilities rely on public health systems – Medicaid or Medicare – to receive medical care, and the process for receiving care through public medical systems affects how much care a person receives. Also, some health disparities are due to the failure of health systems to respect civil rights that CMS regulates and enforces. To prioritize health equity for people with disabilities means that CMS streamlines and strengthens Medicaid and Medicare; holds health systems accountable for civil rights compliance and holds private insurers

¹⁰ Iezzoni, L., et al. (2021, February). Physicians' Perceptions of People With Disability And Their Health Care. *Health Affairs*, 40(2), 297-306. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8722582/>

¹¹ Gloria L. Krahn et al., "Persons with Disabilities as an Unrecognized Health Disparity Population," *American Journal of Public Health* 105, no. S2 (April 1, 2015): S198-S206, <https://doi.org/10.2105/AJPH.2014.302182>.

¹² Gloria L. Krahn et al., "Persons with Disabilities as an Unrecognized Health Disparity Population," *American Journal of Public Health* 105, no. S2 (April 1, 2015): S198-S206, <https://doi.org/10.2105/AJPH.2014.302182>.

¹³ Gloria L. Krahn et al., "Persons with Disabilities as an Unrecognized Health Disparity Population," *American Journal of Public Health* 105, no. S2 (April 1, 2015): S198-S206, <https://doi.org/10.2105/AJPH.2014.302182>.

accountable for prioritizing reimbursement for medically necessary care rather than prioritizing the least expensive care in ways that negatively affect consumers.

Below, The Ability Center has separated our recommendations into specific topics that fall under these requirements:

- **The Medicaid/ Medicare system cannot work without increasing the number of workers drawn to be Direct Care Providers.**

Ohio is experiencing a direct care workforce emergency that puts people with disabilities at risk of institutionalization. People with disabilities and aging members of Ohio are unable to remain independent in their homes due to the workforce shortage. 54.43% of respondents to an Ohio survey marked that there is high turnover in the in-home provider workforce and their in-home providers change often; 40.51% stated that in-home providers are unreliable and don't show up for their shifts; and 29.11% stated that they are sometimes left without in-home providers for weeks at a time¹⁴.

Low wages and a lack of affordable benefits are some of the barriers that lead to staff turnover. Nationally, the average DCW earns \$12.98 per hour. According to a report by PHI, the average hourly wage for DCWs rose from \$11.23 in 2010 to \$12.98 in 2020¹⁵ which does not reflect the increases in costs of living and goods and services. Most individuals are unable to receive a livable wage and are often forced to leave their positions for higher paying jobs with benefits.

With the complex waiver system, workers have difficulties getting timely certification and payment. The Ohio Department of Medicaid (ODM), Ohio Department of Aging (ODA), and Ohio Department of Developmental Disabilities (DODD) oversee seven HCBS Waivers that fund in-home services rather than institutions. However, each agency is siloed in service delivery, payment, and funding. CMS could assist Ohio in providing universal funding to assist these agencies in simplifying their internal systemic processes to certification and ensure that workers are paid on time.

CMS could also work with these agencies to develop professional standards for education, certifications, wages, and benefits. One of the issues we hear to recruiting and keeping a direct care worker under a Medicaid waiver is once the worker hears that DODD pays significantly more for the same services, the worker leaves. The individual who receives a Medicaid waiver is then left without services and is unable to potentially get out of bed, eat, take necessary medications, work, etc. It is imperative that CMS works with these agencies to ensure that workers are paid fair and competitive wages and develop a robust recruitment plan which often depends on the reimbursement rate.

- **CMS must increase enforcement of the Americans with Disabilities Act and other civil rights protections in health care settings, including requiring health care providers to appoint a person to be in charge of compliance. However, CMS must also make it easier to provide accommodations with funding and training.**

While many civil rights protections that are already on the books can help ease health disparities for people with disabilities, health care providers are often unaware of their requirements and do not

¹⁴ The Ability Center of Greater Toledo, Ohio Statewide Disability Needs, Survey Report (2022).

¹⁵ PHI (2021). *Direct Care Workers in the United States: Key Facts*. p.9. <https://www.phinational.org/resource/direct-care-workers-in-the-united-states-key-facts-2/>

follow them without private enforcement. Even once an enforcement action has resulted in a settlement, health care providers often follow only the tenants of that settlement, which usually covers only one issue. For example, the Americans with Disabilities Act requires that hospitals provide patients with disabilities with auxiliary aids and services in order to ensure effective communication. 28 CFR 35.160. In our northwest Ohio region, while our major hospital systems provided American Sign Language interpreters to patients who were deaf, they were only willing to provide it through Video Remote Interpreting because VRI is cheaper and less difficult to provide than in-person interpreters. Because of this, the Deaf Services Center of NW Ohio filed a Complaint with the Disability Rights section of the U.S. Department of Justice. The settlement, from 2019, requires all ProMedica facilities to provide effective communication to patients who are deaf and hard of hearing. In particular, the settlement covers in-person ASL interpreters vs. VRI. See ProMedica Health System Settlement Agreement and ProMedica Toledo Hospital Settlement Agreement, available at https://www.ada.gov/enforce_current.htm.

However, ASL interpreters are not the only form of auxiliary aid and service that hospitals are required to provide, and ProMedica, while following the terms of that settlement, is not up to date on other auxiliary aids and services. Earlier this year, only three years after the DOJ enforcement action, a member of our Center's staff who is hard of hearing went to a hospital covered by this agreement with a patient who is also hard of hearing. Neither patient knows ASL. Instead, both rely on captioning as an accommodation for effective communication. The patient's request to use his phone for captioning resulted in an altercation with the hospital, who claimed that he was recording their conversation and threatened to take away his phone. He was only able to resolve the situation with a patient advocate.

Our Center has also encountered situations where hospitals failed to have accessible medical diagnostic equipment, failed to allow service dogs into hospitals, failed to companions of people with disabilities during "no visitor" policies, and even held discriminatory scarce allocation of resources documents. Civil rights enforcement of one issue, the failure to provide in-person ASL interpreters, took the Deaf Services Center several years, and to do so, they had to attract the attention of the Disability Rights division of the Department of Justice or would have had to hire a private attorney. Now there is a settlement agreement that applies to only one civil rights issue.

CMS needs to promulgate a rule that would require hospital systems to appoint someone in charge of civil rights compliance. There needs to be a person in every hospital who knows disability civil rights and disability culture and knows how to make sure that the medical system works within it.

However, CMS also needs to provide funding and training for civil rights compliance. A recent study showed that physicians do not want to treat individuals with disabilities, partly because it takes too long, and partly because of the need to provide accommodations.¹⁶ Physicians cited issues with architectural accessibility, a lack of accessible diagnostic medical equipment, difficulty communicating with those who use hearing aids or the expense of an ASL interpreter, the inability to provide proper care in a 15 minute

¹⁶ Tara Lagu, Carol Haywood, Kimberly Remold, Christene DeJong, Robin Walker Sterline, and Lisa I. Iezzoni, 'I am Not the Doctor for You': Physicians Attitudes About Caring For People with Disabilities, Health Affairs (October 2022), available at https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2022.00475?utm_medium=press&utm_source=mediaadvisory&utm_campaign=october2022issue&utm_content=lagu&utm_source=Newsletter&utm_medium=email&utm_content=Our%20October%20Issue%3A%20Disability%20And%20Health&utm_campaign=Media%3A%20October%202022%20Combo%20Release.

session, and fear of being sued as reasons they did not want to treat people with disabilities.¹⁷ Better education, training, and funding for accommodations need to be made available to remove some of the concerns by physicians about treating individuals with disabilities.

- **CMS must provide funding for, and better regulate, nursing home transition.**

In Ohio, there are major issues with the way that nursing homes prepare to transition people with disabilities out of the nursing home setting and into their own homes in the community. As a Center for Independent Living, The Ability Center of Greater Toledo has spent much time working in the area of nursing home transition. In accordance with the goals of the Americans with Disabilities Act, and the U.S. Supreme Court case of *Olmstead v. L.C.*, no person with a disability who does not need to be should be stuck in a nursing home. Yet our Medicaid system is still designed to favor nursing home care over home and community based services.

Nursing homes have few regulations that they follow in transition, so when Medicaid/ Medicare stops payment, they are often sent home without appropriate support services. Many nursing home employees do not know what needs to be done to support someone in the community after leaving a nursing home, so The Ability Center has received calls from individuals who are being discharged without appropriate durable medical equipment, enough medication to last them to their first physician's appointment, without having been connected to in-home services, and in extreme cases, without a home. One caller had been discharged to a hotel and called when the money paying for her hotel room was about to run out. One caller, a double-amputee, was discharged from a nursing home without a wheelchair. Without intervention from Centers for Independent Living, and sometimes Ombudsman, many nursing homes discharge people without appropriate transition planning.

CMS must better regulate and enforce the discharge planning process. Also, CMS must fund nursing home transition.

- **CMS should streamline access to home- and- community- based- services. HCBS should be available under state plan Medicaid rather than be an exception to state plan Medicaid that creates extra barriers to apply for services and requires a state match.**

Home and Community Based Services are still seen as a Waiver/ and exception rather than part of the state plan Medicaid, which causes a barrier to entry. A person must both go through the process of qualifying for Medicaid and then go through a separate process of applying and qualifying for an HCBS Waiver. Because Waivers are set up as an exception to the normal rules, they also create a large bureaucracy that people must wade through just to receive appropriate services in their homes. People must apply for HCBS waivers separately, which means they must know how, they could be denied, and if denied, they have to go through an appeal process. States, too, must apply for waivers, which is a long bureaucratic process that can take years.

In Ohio, three different Medicaid agencies apply for HCBS Waivers, which means that each Waiver is under one of three different systems, with different local agencies and parties involved, and three different sets of regulations with different eligibility standards. HCBS Waivers also seem to be often offered as a "trial program" so that specific Waivers, with specific eligibility that provide certain services, are around for a few years and then no longer there. The siloed nature of Waiver programs and

¹⁷ Id.

eligibility also means that our state Medicaid departments are deciding how much funding is available for each home-and-community based service offered under a Waiver rather than medical necessity determining what is available. In short, a state can decide to restrict services based on what is available under each of our nine different HCBS Waivers.

CMS should phase out the HCBS Waiver system and ensure that states make HCBS services available under state plan Medicaid through 1915(i). In that way, a person with a disability would simply apply for Medicaid, be found eligible, and then submit the required documentation to receive HCBS. It would eliminate the need for states to create an entire separate system for HCBS Waiver provision and simplify the process, rules, and politics of the Medicaid system.

The use of the “medical necessity” legal standard for non-medical home and community-based services, like home modifications, also results in a legal standard that is difficult to enforce. In one home modification denial hearing, my client’s occupational therapist had examined her home and recommended a bathroom modification and wider hallways, and the Medicaid agency, who had never been to her home, claimed it was not medically necessary. Yet another person on a Waiver was approved to have a porch built on the back of her home.

- **CMS should hold Managed Care Companies, often given the authority to regulate public health systems, accountable or eliminate them.**

Managed care creates more bureaucracy and puts companies that are incentivized to make profit in charge of paying for health care and community-based supports. Companies who provide managed care change from year to year so that a person doesn’t have a regular care provider. Patients don’t have a defined point of contact so that it can take hours to reach someone who knows what is happening with their case, and once they reach someone, that person may not know and patients cannot reach that same person again. Appeals of denials always favor the managed care company, even though they are often made without appropriate evidence, aka, though patients have a script from their physician for something covered by their Medicaid, they are denied because of evidence or an evaluation from an “expert” who has never met or evaluated them. Who you know and standing in the community often matters more in getting medical care covered than whether a doctor has certified it is medically necessary – for example, one person was approved for a “home modification” of an outdoor porch while another could not get approval to have their bathroom and doorways modified despite relying on a wheelchair to get around in an older home.

Topic 4: Impact of the COVID-19 Public Health Emergency (PHE) Waivers and Flexibilities

Overall, The Ability Center of Greater Toledo is in favor of easing bureaucracy and making reimbursement for medical care and home and community-based services easier for people with disabilities and their providers. Many of the flexibilities that were granted as part of the COVID-19 Pandemic, if continued, could increase the number of providers available to people on Medicaid, make it easier to receive care, and remove some of the barriers to entry caused by unnecessary steps and regulations to receive care. We especially recommend some of the steps taken that eased the number of steps required to become a provider; allowed payment for family caregivers; and expanded the availability of telehealth.

Some of the modifications made in Ohio that we would like to see continued are:

- Telehealth enhanced to make reimbursement consistent with present FFS policies
- Prior authorizations for medication granted auto renewal without clinical review
- Waiver of prior authorization requirements
- Waiver requirement for in person pre-admission screening and resident review evaluations and assessments
- Waiver unit of service limits for home health and private duty nursing
- allow remote technology for assessments for wheelchairs and accessories
- expanding service setting to allow adult day services and vocational rehabilitation providers to furnish services in residential settings and remotely
- permitting payment for direct services rendered to minor children by family caregivers or legally responsible guardians who are employed by an agency
- modifying provider qualifications to allow for training and onboarding; allowing providers an active Medicaid ID to furnish waiver services across delivery systems; and waiving background checks for new providers
- modifying provider types to allow ADS and Voc Hab providers to receive certification in homemaker/ personal care; participant directed HPC and respite.

All of these flexibilities have increased people with disabilities' access to care in Ohio, and we recommend that they be continued post-COVID.

We appreciate the opportunity to provide this important feedback to ensure that healthcare and related programs and services are expanded for people with disabilities. Bureaucratic policies often make it more difficult for people to access medical services and we are hopeful that CMS can expand their policies and procedures to advance healthcare access. If you have any questions, please contact the undersigned.

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