VIA ELECTRONIC SUBMISSION

August 31, 2022

Re: Medicare Advantage Request for Information

Chiquita Brooks-LaSure, Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS-4192-P, P.O. Box 8013,
Baltimore, MD 21244-8013

Dear Administrator Brooks-LaSure:

DREDF is a national cross-disability law and policy center that protects and advances the civil and human rights of people with disabilities through legal advocacy, training, education, and legislative and public policy development. We are committed to increasing accessible and effective healthcare for people with disabilities and eliminating persistent health disparities and inequities that affect the length and quality of their lives. DREDF’s work is based on the knowledge that people with disabilities of varying racial and ethnic backgrounds, ages, genders, and sexual orientations are fully capable of achieving self-sufficiency and contributing to their communities with access to needed services and supports and the reasonable accommodations and modifications enshrined in U.S. law.

We applaud CMS for seeking feedback on ways to strengthen Medicare Advantage (MA) that align with the Vision for Medicare and the CMS Strategic Pillars. Our comments expand on Question # 2 and # 10, under Advancing Health Equity, regarding the need for data and the use of algorithms and artificial intelligence in healthcare decision making by MA plans and providers. We urge CMS to act quickly to adopt policies and provide guidance that reflect these advocacy stakeholder recommendations.

Q # 10: Algorithms

Introduction

States, health plans, and healthcare providers increasingly are using algorithms and devices driven by artificial intelligence (AI) to support clinical decision making and establish clinical care standards. These tools are also widely used to support and inform population health
management. We appreciate that CMS is seeking input on the effectiveness and impact of these tools on Medicare Advantage (MA) beneficiaries. We also appreciate that CMS recognizes the need for algorithmic fairness and that algorithmic bias can drive differential outcomes that exacerbate inequities.¹

Even as this evolving technology holds great promise for improving healthcare and health outcomes, it also can contribute to discrimination and amplify certain structural barriers and inequities that affect marginalized groups, including people with disability. Important work has been done that identifies how disability bias in algorithms negatively affects, for instance, employment decisions, determination of the need for Medicaid personal care services in the home, and ability of autonomous vehicles to recognize pedestrian wheelchair users.²,³,⁴ Race and ethnicity bias in certain algorithmic tools and AI also has been well documented.⁵ Yet, very little work has been done to understand how bias in algorithms and AI affects people with disability in healthcare even as it has the potential to profoundly affect healthcare decisions, services, and outcomes for this large population. Moreover, when disability intersects with other marginalized identities, algorithmic and AI bias can further stigmatize patients, misdirect resources, and reinforce or ignore barriers to care rather than serving as a pathway to improving treatment and health outcomes.

We specifically want to draw your attention to the potential impact of disability bias in algorithms and AI being used in healthcare and services decision-making and recommend steps CMS should take to ensure that these biases are identified and corrected. The goal is to increase equity and fairness and avoid discrimination and inappropriate care decisions for disabled Medicare Advantage beneficiaries.

Disability prevalence

Data supports the need to understand how disability bias can affect development and use of algorithms and AI. It should also inspire MA plans and providers to take steps to ensure appropriate disability inclusion and transparency and establish patient appeal mechanisms when outcomes are suspected of negatively affecting patient care and services. In 2022, nearly 28 million individuals were enrolled in Medicare Advantage.⁶ Disability prevalence is high among this large group based on national disability data for people over age 65. About 61 million Americans report having a disability. Disability increases significantly with age and disability prevalence is higher among members of multi-marginalized communities including African Americans and Hispanics. About 40 percent of individuals in these demographic groups who are over age 65 report a disability.⁷ Even as most Medicare beneficiaries are age 65 and older, 17 percent are under age 65 and qualify for Medicare because of a permanent disability. Among the younger group, a large number are members of multi-marginalized groups: 31 percent are African American, and 23 percent are Hispanic as compared with only 14 percent who are white.⁸ Furthermore, identified inaccuracies in Medicare data hinder the
identification of race and ethnicity disparities among Medicare beneficiaries. These deficiencies emanate from the source data and the use of algorithms, according to the HHS Office of Inspector General.\(^9\)

Extensive research supports the fact that disabled people experience barriers to care that result in substandard treatment and that affect health outcomes.\(^{10,11}\) Adults with disability report foregoing or delaying necessary care and having unmet medical needs compared to people who do not have disabilities.\(^{12}\) Deferring care results in poorer health outcomes. Patients with disability report physical and architectural barriers, exam equipment that cannot accommodate individuals with various functional limitations, inflexible office procedures and processes, negative attitudes, and lack of training and awareness about treating patients with disability among physicians, nurses, and other health care personnel. Patients with mobility disabilities report they are rarely weighed or examined on an accessible exam table and patients who are Deaf report that Sign Language Interpreters are often not available for medical visits. Fewer MA members were able to get mental health and substance use disorder care in 2022 as compared with 2021.\(^{13}\) Barriers to care for these individuals likely include too few mental health specialists with experience working with people with certain functional limitations, such as those who are Deaf or who have intellectual and developmental disabilities. It is also likely that MA plans and providers are not fully aware of these needs, thus care is inadequate, and members of these groups are likely to experience mental health care disparities. When accommodations and appropriately trained providers are absent, healthcare for people with disability is inequitable.\(^{14}\)

**Possible effects of disability bias**

Although research is limited, some scholars have observed that when algorithmic and AI development and testing does not consider the potential for disability bias, certain inequitable outcomes could occur. For instance, when health plans use algorithms to assess patient risk and rank patients for certain care and services, such as enhanced care management, some people with disabilities might be missed if the ranking tool relies on care utilization as a proxy for severity of disease and thus eligibility for the enhanced service. That is, the algorithm understands that higher utilization equates with more extensive illness and greater health needs while lower utilization signals better health and fewer health needs. Since disabled people report underutilizing care due to widespread barriers, the algorithm might interpret their underutilization as an indicator of a lower level of disease and therefore does not identify them for enhanced care management in the absence of other qualifying factors.

Moreover, other specific disability information is not measured or recorded directly within electronic health records (EHRs), yet it is likely that disabled people have a pattern of healthcare services use that might display unique variation based on disability type and might
be affected by intersectional and demographic factors including race, ethnicity, gender identity, and age. To avoid creating a prediction tool that performs prejudicially when assigning scores to disabled patients, it is critical that disability be considered during the algorithm’s creation, particularly since MA enrollment includes many beneficiaries with disability. Thus, any risk assessment algorithm should be designed with explicit attention to disability, not as an outlier or source of skew, but as a common demographic characteristic—an aspect of the human condition.

In another example, EHRs typically do not include either functional limitation data for patients with certain vision, hearing, mobility, cognitive, developmental, or other disabilities, or related accommodations required for equitable care. Such accommodations include, for instance, ASL interpreters, accessible medical and diagnostic equipment such as height adjustable exam tables, wheelchair accessible weight scales, and modified policies or procedures including extended exam time or lifting assistance. Thus, when EHR information is used as a primary data source, algorithms will not identify patients who might require accommodations for effective care. Algorithms, therefore, are necessarily missing critical data about the kinds of health-related accommodations patients with disability require, but often do not receive, and outputs could undercut an accurate assessment of the extent to which they consequently are at risk or are underserved in health care.

Recent emphasis on social determinants of health illustrates that not all health outcomes are closely related to clinical care. Other factors, including income, food insecurity, neighborhood characteristics, and available transportation play equally important roles. The presence or absence of accommodations in healthcare for people with disability are recognized as social determinants of health. In these examples, it is not enough to simply use diagnostic categories, such as arthritis, as a primary point of information from which other needs can be inferred. A diagnosis of arthritis alone does not signal a need for accessible medical and diagnostic equipment. This critical gap in data influences the accuracy and effectiveness of predictive tools and can result in under identification or misidentification of people with disability for services or other interventions.

Research has also found that negative patient descriptors in the EHR, perhaps the result of implicit racial, disability, or gender identity bias, can also exacerbate health and healthcare disparities and may be incorporated into algorithmic design. Recent reports suggest that many companies, operating without regulatory oversight, sell algorithms to healthcare providers that guide patient care despite the presence of racial and other biases in the tool. Some tools are being used to help identify potential illness before it manifests. For example, an AI tool in wide use that helps identify patients at risk for sepsis has come under criticism for failing to identify correctly certain patients who are at high risk based on their diagnosis, medical status, and other factors. Disability advocates and researchers are concerned that the
absence of nuanced disability-specific information in the EHR data the algorithm uses to predict outcomes affects its capacity to predict sepsis accurately. Since these tools are proprietary, they cannot easily be interrogated for such biases.

Algorithm and AI researchers focusing on fairness and transparency recommend specific actions to address these issues. We strongly urge CMS to consider issuing regulations, guidance, and policy clarifications that will deliver the message to companies developing these tools that federal healthcare programs will not tolerate discriminatory healthcare and services decisions that undermine patient care and perpetuate unequal treatment of certain demographic groups, including people with disability. Moreover, the absence of any discussion of race, ethnicity, disability, or any other personal characteristic should not be taken as evidence of an unbiased neutral approach. Rather algorithm and health AI developers should bear an active burden of demonstrating to CMS, and to the public, how their algorithm works to mitigate historic inequities and biased failures to consider all information that is relevant to an accurate assessment of health risk. Such actions will help plans and providers understand and evaluate how the tools they elect to use can perpetuate bias that affects patient outcomes.

**Recommendations**

Certain concrete steps would acknowledge these problems and begin to build long-term solutions: improving datasets, auditing to prevent and remediate algorithmic disability bias, establishing standards for external oversight and regulation, developing disability inclusive ethics, and establishing appeals processes.

**Improving datasets**

To identify disability-related discrepancies in algorithmic performance, people with disability must be accurately identified within datasets. Furthermore, because of the mounting evidence that individuals with intersecting identities are particularly likely to experience biased treatment from algorithms, additional effort must be dedicated to gathering disability data that adequately represents the complexity and heterogeneity of the disability community. This means that examples of disabled people must demonstrate a variety of disability types, include people of color and from diverse racial and ethnic backgrounds, people with a variety of gender identities and presentations, and people of a wide range of ages. Additionally, the heterogeneity of the disability community requires that extra consideration be given before omitting or removing “outliers” from the dataset, as many of the standards against which data are judged to determine their accuracy routinely exclude disabled people. Increasing and improving disability data may mean creating more inclusive processes for the determination of outlying data. Collecting more and better disability data will also include establishing standards and procedures for increasing the quality and inclusion of disability data, appropriately protecting
and governing data, and responsibly integrating data with existing datasets to avoid exposing people with disabilities to unnecessary risks.

**Auditing to prevent and remEDIATE algorithmic disability bias**

Specific steps must also be taken to mitigate and ideally, prevent, biased treatment of people with disability by algorithms and AI used in healthcare decision making. For example, experts have proposed developing standards for algorithmic accountability, highlighting different elements of algorithmic systems that must be considered to prevent bias.\(^\text{19}\) Others have suggested specific questions that should be asked of a model to understand its potential for adverse impacts, and to determine whether it may warrant additional examination to prevent biased outcomes.\(^\text{20}\) Another critical element is ensuring that people with disability are fully included in the development process. One way is through the use of participatory methods. Participatory methods have been proposed within the context of other situations in which algorithms are used, often as work to acknowledge and rectify the tendency for algorithms to reinforce existing power structures.\(^\text{21, 22}\) Recent research into preventing algorithmic bias has noted that while algorithmic bias can emerge at any stage of development, critical issues most commonly emerge during early steps.

**Establishing standards for external oversight and regulation**

Like datasets, algorithms themselves should be subject to outside oversight and auditing. Audits should be conducted both by external experts who were not involved in development of the algorithms under review, as well as people with disability. Establishing independent audit panels thus can support greater connection and collaboration between technical experts and people with disabilities.

**Developing disability inclusive ethics**

Seemingly neutral technologies incorporate biases that are present in the societies from which they emerge. Therefore, an important overarching aspect of the work to ensure that healthcare algorithms and AI are fair and equitable for people with disability involves working towards full and equal partnerships with us during the design, development, and implementation stages. Ideas need to be based upon a sense of ethics that recognizes the full humanity of people with disability and protects their rights within society. Ethics codes often do little to support vulnerable groups and rarely create real accountability to such communities, often due to a lack of authentic engagement with them.\(^\text{23}\) Similarly, although many of the prescribed responses to algorithmic bias, such as those that emphasize fairness, accountability, and transparency, offer up solutions, they ultimately do little to shift established balances of power
unless accompanied by consideration of who gets to decide what is fair, accountable, or transparent.  

Establishing a notice and appeal process

Algorithms run the risk of replicating human biases and injustices that exist within the status quo. Consequently, CMS should require MA plans and providers to inform patients that algorithms and AI tools might be used to inform decisions about their eligibility for services and treatments. A clear appeal process should be provided if disputes arise over treatment or services decisions in which algorithms or AI tools had been used. For instance, patients might not have been identified for services to which they think they are entitled, such as enhanced case management, based on the risk stratification tier assigned by an algorithm. They should be able to access the audit, stratification, or evaluation results and appeal the tier assignment or other decision through an accessible, straightforward process.

Q # 2: Data

People with disability are among the population groups that experience significant health disparities. They engage in preventive care at lower rates than recommended and report unmet healthcare needs. They delay or go without recommended care for a variety of reasons including disability related access barriers, such as provider inaccessibility, lack of accessible medical diagnostic equipment, and lack of necessary accommodations in healthcare settings. Health and healthcare disparities are compounded when disability intersects with race, ethnicity, gender identity, and age. Medicare Advantage enrollees are likely disproportionately affected by these disparities because disability prevalence is high among the group, especially for members with multiple marginalized identities.

Disability, like race, ethnicity, and gender identity, is a bona fide demographic category. Therefore, health plans and providers should be collecting disability status information as a core demographic data element. Collecting disability status using functional limitation questions will allow for better measurements of the social determinants of health and more comprehensively support health equity for this demographic group. For over a decade, advocates and researchers have called for adding functional limitation measures to patient electronic health records (EHRs). This will help providers to identify patients’ need for accommodations during clinical visits and hospitalizations and to understand the interaction of these characteristics more fully with diagnoses and other clinical findings. While providers typically rely primarily on symptoms and diagnoses to inform their perception of patients’ clinical profiles and need for care, these factors are ineffective as a proxy for functional limitations, which can vary widely within the same diagnostic category. Moreover, accommodation needs rarely can be inferred solely from diagnosis. Frontline provider staff
cannot be expected to process effectively detailed clinical information, across a wide variety of patient disabilities and chronic health conditions, to ensure that individuals are accommodated and receive effective care. Therefore, MA plans and providers should invite patients, at registration and when scheduling appointments, to self-identify any functional limitations and their answers should be added to the EHR. Those who self-identify functional limitations should also be provided an opportunity to specify any needed accommodations and that information should also be added to the EHR. Including this information in the EHR is especially important for MA beneficiaries who experience a high prevalence of disability. Moreover, this data is required for other purposes, such as research, disaster planning, and responses to public health crises as evidenced by the COVID-19 pandemic. Lack of accurate functional limitation data for people with disability masks the need for policies and procedures that would improve access to care and health outcomes and undermines the delivery of affective, equitable, patient care.

Models exist for collecting functional limitation data that could be a starting point. For instance, the six-item set of disability questions used by the American Community Survey (ACS) and other major federal surveys is currently the minimum standard for collecting data on disability. This question set has been tested and validated and has the additional benefit of facilitating interoperability with census data. In 2013, Oregon passed legislation requiring health care providers to collect data on race, ethnicity, language, and disability, and share the information with the Oregon Health Authority. Covered entities now collect answers to nine functional limitation questions in the domains of hearing, seeing, walking or climbing stairs, remembering or concentrating, learning, communicating, bathing or dressing, and doing errands alone. One question asks patients with mental health conditions about mood, feelings, and ability to control behavior. Because these questions are in use in the field, they offer a model that CMS could adopt for MA plans and providers to use.

Several academic medical centers, including the University of Michigan and the University of Colorado, Anschutz, have been testing methods to collect functional limitation data. Some of their findings appear in published research that can inform CMS actions on this issue.

A well-documented barrier to collecting disability data is the lack of question fields on functional limitations in health information technology, such as EPIC. Recently, however, advocates have been working with the Office of the National Coordinator for Health Information Technology (ONC) on the US Core Data for Interoperability (USCDI). This year, three disability-related data elements within the new health status data class have been added to USCDI v3. The Health Information Technology Advisory Committee (HITAC) adopted the Interoperability Standards Workgroup Report to the Health Information Technology Advisory Committee, including its recommendations for changes to USCDI v. 3 that were incorporated
in the final USCDI report issued in July 2022. Disability advocates support the detailed recommendations made in the Interoperability Standards Workgroup Report. (See “Documenting Disability: Brief Presentation.”) Advocates representing disability rights and healthcare organizations recommended seven functional limitation domains: hearing, vision, mobility, decision making, dressing and bathing, doing errands alone, and communicating. The fact that the USCDI is making progress toward requiring that disability data fields be included in HIT sends an important message to CMS, health plans, and providers that healthcare entities may no longer ignore the importance of collecting demographic data for patients with disability. They should begin taking necessary steps now to integrate functional limitation questions in their EHRs.

Each of the data collection models previously described offer a possible method that CMS could sanction and require MA plans and providers to adopt going forward.

**Recommendations**

CMS should adopt the disability data recommendations from the 2022 ONC USCDI Interoperability Standards Workgroup Report and, as a starting point, require MA plans and providers to collect functional limitation data using these questions.

Years of research has shown that health plans and providers should collect functional limitation data for the demographic group, patients with disability, and record the data in patient EHRs. As a starting point, CMS should adopt the recommendations for data collection published in the Interoperability Standards Workgroup Report. (See “Documenting Disability: Brief Presentation.”) It should require MA plans and providers to phase in use of the tool and provide related technical assistance and support as implementation commences.

Thank you again for the opportunity to comment.

Sincerely,

Mary Lou Breslin
Senior Analyst
ENDNOTES

1 Researchers have defined algorithmic bias as “…the application of an algorithm that compounds existing inequities in socioeconomic status, race, ethnic background, religion, gender, disability, or sexual orientation and amplifies inequities and health systems.” Panch, Trishan et al. “Artificial intelligence and algorithmic bias: implications for health systems.” Journal of global health vol. 9,2 (2019): 010318. doi:10.7189/jogh.09.020318


17 We wish to thank Ian Moura, DREDF's 2022 Marilyn Golden Policy Fellow, for his invaluable research and analysis on use of algorithms and AI in health care.


20 Trewin et al., 2019.


US Census Bureau, “How disability data are collected from the American Community Survey.” (2021). https://www.census.gov/topics/health/disability/guidance/data-collection-acs.html. It should also be noted that this question set is limited in that it does not collect information on certain functional limitations such as communication difficulties, limitations due to mental health symptoms, or learning or intellectual differences.


See Michael M. McKee, MD, MPH, Associate Professor, Center for Disability Health and Wellness, https://medicine.umich.edu/dept/family-medicine/michael-m-mckee-md-mpm.

See Megan Morris, PhD, MPH, Associate Professor, Division of General Internal Medicine, Director of Learning Collaborative to Address Disability Equity in Healthcare, https://medschool.cuanschutz.edu/accords/research-publications/investigator-spotlight/archived-investigator-spotlights/megan-morris.


HealthIT.gov, Interoperability Standards Workgroup.