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May 4, 2021

Agency for Healthcare Research and Quality
Department of Health and Human Services
5600 Fishers Lane
Rockville, MD 20857

RE: RFI on the Use of Clinical Algorithms that have the Potential to Introduce Racial/Ethnic Bias into Healthcare Delivery.

To Whom It May Concern:

The National Health Law Program (NHeLP) is a public interest law firm working to advance access to quality health care and protect the legal rights of low-income and under-served people. NHeLP has a long history of advocacy regarding the use of automated decision-making systems (ADS), including algorithms to determine health care eligibility and services.¹ We are particularly familiar with how the lack of transparency of many ADS impacts individuals' ability to understand and fight care denials or reductions. We have also seen how poor transparency in the ADS development and implementation process obscures opportunities for evaluation of errors or bias in these systems. We appreciate the opportunity to provide information about the use of clinical algorithms and bias in health care delivery.²

We commend AHRQ for its intent to commission an evidence review on commonly used algorithms. Our long history with ADS repeatedly demonstrates how important an examination of development and validation, including validation over time, is to determining whether a given ADS is still working appropriately.

We have four overarching asks of AHRQ as it continues in this algorithm evaluation process:

(1) Transparency of ADS Throughout the Life-Cycle:³

While we appreciate that AHRQ is asking for information regarding existing ADS, this requested information is not commonly available about many of the ADS used to make health care decisions. Many health care ADS are shielded behind intellectual property protections and are not available for examination, much less the underlying study, training, or validation data.⁴ This is true even when ADS is used for governmental purposes.⁵ As described below, much of the advocacy and litigation in the Medicaid realm about ADS has been about the failure to provide even minimal information to an impacted individual about the system that informs what health care will or will not be provided to them.

¹ NHeLP has a long history of litigation and advocacy on issues that involve ADS in Medicaid including problematic eligibility computer systems that fail to timely and accurately determine eligibility or that wrongfully terminate eligibility; ADS that limit services; complex assessment systems for home and community based service level care and resource allocation decisions; and a variety of ADS related issues in between. Throughout this advocacy we commonly encountered states struggling to make changes to systems, including to provide legally sufficient notices to individuals affected by the systems. Our experience with advocating for meaningful due process protections around many ADS has reinforced the importance of the process around the systems that protect the interests of the individuals affected because it is unlikely a given ADS will always be able to accurately determine the needs of every individual it encounters.

² AHRQ, Request for Information on the Use of Clinical Algorithms that have the Potential to Introduce Racial/Ethnic Bias Into Healthcare Delivery, 88 Fed. Reg. 12948 (Mar. 5, 2021), <https://www.govinfo.gov/content/pkg/FR-2021-03-05/pdf/2021-04509.pdf>.

³ NHeLP would like to acknowledge the role the years-long thought partnerships with Kevin de Liban of Legal Aid of Arkansas, and more recently Emma Weil, Emily Paul, Aaron Rieke, and Ming Hsu of Upturn, has played in helping us develop some of the theories included in these comments.

⁴ See, e.g., Rebecca Wexler, *Life, Liberty, and Trade Secrets: Intellectual Property in the Criminal Justice System*, 70 STAN. L. REV. 1343 (2018), <https://review.law.stanford.edu/wp-content/uploads/sites/3/2018/06/70-Stan.-L.-Rev.-1343.pdf>; Kate Crawford & Jason Schultz, *AI Systems as State Actors*, 119 COLUMBIA L. REV. 1941 (2019), <https://columbialawreview.org/content/ai-systems-as-state-actors/>.

⁵ *Id.*; see also *Salazar v. District of Columbia*, 596 F. Supp. 2d 67 (2009) (granting access to Interqual Clinical Decision Support Criteria to a limited group of individuals, despite objections regarding trade secret protections, to enable an evaluation of whether children were being improperly denied services based on this criterion in violation of a settlement agreement regarding children's access to medically necessary Medicaid services).



We believe that the whole life-cycle of an ADS—from the original identification of a problem to be addressed by an ADS, including the primary question or issue and identified limits, through various stages of development and implementation, to ongoing implementation and quality control—needs increased transparency and oversight. Each of those stages involves decision points that are opportunities for bias. In addition, ongoing data about the use of an ADS needs to be publicly available to study potential disparate impact from systems that may appear facially neutral. Until that transparency exists, a review of current biases in ADS will be incomplete. We ask that AHRQ acknowledge this transparency issue in any results published from its review and recommend transparency improvements to all stages of the process.

(2) Evaluate Health Care ADS for More than Racial/Ethnic Bias

We ask that AHRQ expand its examination beyond how race/ethnicity and related variables impact health care use, patient outcomes, and health care disparities. NHeLP recognizes the centrality of race and ethnicity in an examination of bias, including institutional bias, in health care. A well-designed evidence review should be able to include additional factors such that AHRQ has a more complete picture of the potential biases in existing health care algorithms. As our comments below discuss, data collection, research, and analysis of people within the health care system has long had a narrow view of identity. Our experience has identified ADS bias regarding race, ethnicity, disability, age, sexual orientation, gender identity, and other factors. Much like in the financial sector, health care has such systemic, institutionalized bias that it is very difficult to separate and draw conclusions from existing data. While we recognize that including more factors for evaluation may complicate AHRQ's task, we believe it would be an incomplete evaluation without doing so.

(3) Center the Experience of the Individual Impacted by the Health Care ADS

NHeLP has spent decades working to ensure that people have access to quality health care for low-income and underserved individuals. Throughout our work we have encountered time and again instances where medically necessary health care is denied by policies and processes about which the affected individual has very little, if any, information. Because our work largely centers on Medicaid, we have often been able to use Constitutional due process arguments to force greater transparency and protections for individuals. However, our experience has taught us that the rise of ADS has exacerbated the problem of “black box” health care decision-making. This has multiple

impacts. A person denied care may simply be told the results of the ADS without any information about what about their condition triggered the denial, which may deter appealing the denial.⁶ Even if a State is willing to make changes to information provided, limitations of an ADS may make that incredibly difficult. Inquiries into systemic issues identified may be unaddressed because the system is not designed to facilitate investigations, including running simple reports, to identify potential issues, including disparate impact. And very rarely is there any meaningful opportunity for public comment on an ADS, which should include information on the purpose, data sources, analyses, validation, implementation plan, and other decision points.⁷ Our experience has taught us there inevitably will be problems with these systems, therefore the process around the use of ADS is equally or perhaps more important than the system itself—is there a readily available, accessible, and understandable process with clear criteria and timelines a person can access when an ADS has had an adverse impact on them and they need to ask for an exception to that decision? Can they continue any current benefits affected by the ADS during this process without fear of having to pay them back? Such a process provides a critical safety net to the use of ADS.

While we appreciate the science-based inquiry from AHRQ's RFI, it asks very little about the impact on individuals affected. Much of the research on ADS discusses the potential for bias at a very high level and may include suggestions about technical solutions. But at the core of the concern about bias in ADS is that people are being denied health care that is medically necessary for them—not them as a member of a population group, but as an individual with their own characteristics and medical needs. AHRQ's RFI asked whether patients are aware of the inclusion of race/ethnicity or other variables that can result in bias and whether that is understood, but did not ask how

⁶ Jane Perkins, Nat'l Health Law Program, Q&A: Using Assessment Tools to Decide Medicaid Coverage (June 9, 2016), <https://healthlaw.org/wp-content/uploads/2016/06/QA-Case-developments-May-20162.pdf>; Jane Perkins, Nat'l Health Law Program, Ensuring that Assessment Tools are Available to Enrollees (Sept. 10, 2015), <https://healthlaw.org/resource/ensuring-that-assessment-tools-are-available-to-enrollees/>; David Machledt, Nat'l Health Law Program, Medicaid Assessments for Long-Term Supports & Services (LTSS) (May 5, 2015), <https://healthlaw.org/resource/medicaid-assessments-for-long-term-supports-services-ltss/>; David Machledt, Evaluating Functional Assessments for Older Adults (June 13, 2017), <https://healthlaw.org/resource/evaluating-functional-assessments-for-older-adults/>.

⁷ See, e.g., Elizabeth Edwards & Sarah Grusin, Nat'l Health L. Program, [*Opportunities for Public Comment on HCBS Assessment Tools - National Health Law Program*](#) (2019) (discussing the limited opportunities for public comment on ADS in the form of assessment tools used in Medicaid).



individuals experience the use of ADS to determine their health care. To understand bias in any system, there must be an understanding and acknowledgement of how that bias harms people. Identifying potential solutions to a harm must center those impacted in order for any solution to truly work. Therefore, we ask that AHRQ not lose the human element in a discussion about data, algorithms, ethics, and policy solutions.

(4) ADS Will Be Imperfect and Biased. The Safety Net for its Decisions Must Not Be.

Given the potential sources for bias, it is unlikely that health care ADS will ever be perfect, therefore the process around the systems is an effective area for meaningful change and protection. From the front end, people should be able to easily understand how data collected about them will be used, in the short and long-term, and require informed consent to collect and use that data. The result of most ADS is a person denied or approved for health care, thus any approach to ADS must ensure that an impacted individual can understand the decision that has been made, has access to the necessary information, and has access to a process that allows them to say that decision was wrong and access the care they need.

I. Increase Transparency for ADS Throughout the Life Cycle

ADS in health care is not particularly unique in terms of potential sources of bias. Like ADS in other sectors, health care ADS are socio-technical in nature: they are a mix of human judgement, statistical models, and software whose purpose and constraining policies are equally important as their technical particulars.⁸ Transparency of these elements is fundamental. Obermeyer et al.'s oft-cited discussion of racial bias in a health care algorithm would never have been written if that algorithm's training data, objective function, and prediction methodology were not available.⁹ This transparency must also include attempts to correct for bias within a system or to engineer ethics into a system.¹⁰

⁸ Aaron Rieke, Miranda Bogen & David G. Robinson, Upturn & Omidyar Network, *Public Scrutiny of Automated Decisions: Early Lessons and Emerging Methods* 5 (2018), <https://omidyar.com/wp-content/uploads/2020/09/Public-Scrutiny-of-Automated-Decisions.pdf>.

⁹ Ziad Obermeyer, *Dissecting Racial Bias in an Algorithm Used to Manage the Health of Populations*, 366 SCIENCE 447 (Oct. 25, 2019), <https://science.sciencemag.org/content/366/6464/447>.

¹⁰ Melissa D. McCradden et al., *Ethical Limitations of Algorithmic Fairness in Health Care Machine Learning*, 2 THE LANCET E222 (May 2020).



Although there is often much focus on the technical system itself and whether the ADS is programmed to be biased or create biased results, bias can impact that technical system before any coding begins. Decisions all along the way generate opportunities for bias to be introduced to the system, from the initial decision to develop an ADS, to development design, data selection, data analysis, evaluation, choice of ADS, testing and validation, implementation, ongoing quality control, points of human involvement, and the process for any revisions to the system.¹¹

Calling an ADS a “race-neutral” system does not address these points of bias. Even in systems that do not explicitly factor in or address race, or other protected classes, their statistical models can incorporate biases in ways that are difficult to detect, even if one is looking.¹² To even try to identify bias in an ADS, an investigation must understand the ADS’s life cycle and have documentation of decisions made along the way, along with the technical knowledge to understand the training data, executable code, test results, and other information.¹³

A. The Decision to Use ADS

Determining the original intent behind the decision to use an ADS is important. In our experience with ADS, the systems are often adapted from research that had a different purpose or asked a slightly different question originally compared to how that ADS is currently being used. For example, many Medicaid home and community based services (HCBS) assessment ADS are based on institutional data or rather small samples that were intended to help identify service needs. In practice, they are used to control costs and limit services.

In another example, utilization management tools may be centered more on financial measures than widely accepted clinical criteria.¹⁴ Often, ADS are created under the banner of

¹¹ David Lehr & Paul Ohm, *Playing with the Data: What Legal Scholars Should Learn About Machine Learning*, U.C. DAVIS L. REV. 51 (2017) (describing machine-learned systems as “complicate outputs of intense human labor-labor from data scientists, statisticians, analysis, and computer programmers...Along the way, they have the power to affect the running model’s accuracy, explainability, and discrimination”).

¹² Anupam Datta et al., *Proxy Discrimination in Data Driven Systems* (2017), <https://arxiv.org/pdf/1707.08120.pdf>.

¹³ *Public Scrutiny of Automated Decisions*, *supra* note 8.

¹⁴ See, e.g., *Wit v. United Behavioral Healthcare*, 14-cv-2346-JCS, 2019 WL 1033730 (N.D. Cal. July, 27, 2020) (although not explicitly an ADS, discovery into utilization management tools found that the



increased efficiency and objectivity, but the underlying rationale behind the initial decision may instead prioritize cost-savings at the expense of patients' needs. The use of ADS may even be more the result of successful efforts by sales people or lobbyists about the purported benefits of a given ADS. Systems that were originally built to target fraud might be adapted as data sources for decisions regarding services or eligibility.¹⁵ Therefore, it is critically important to articulate both the need for an ADS and its underlying purpose. Was it developed as part of cost-saving measures to allocate care in a very resource-limited system? Was it developed by a rural health clinic and is now being applied much more broadly? Was it intentionally developed to answer a specific question with research designed to address that question with identified variables? Or was it developed in response to research that identified certain correlations among a study population and expanded to an ADS for clinical purposes? Much like any scientific study, examining the original question or hypothesis itself can reveal potential bias or at least potential sources of bias that deserve closer examination.

B. The Development of ADS

Decisions made during the development of ADS can introduce significant bias into the system. Choices about how to design the ADS, the data to be used, analysis to be applied, what populations it will be applied to, the audit trail and other quality control mechanisms, etc. are all very fraught with potential bias. Key steps and choices in the development process are likely driven by available resources and funding. This may result in choices that prioritize performance, cost-savings, or ease of use by practitioners over protections against bias or quality control mechanisms.

For example, Medicaid eligibility systems ADS often focus on efficiency and performance measures.¹⁶ Advocates have reported that those ADS struggle to identify errors or outliers as the reporting functions necessary to find those issues, and the people affected, were not built into the system. Either as part of the original contract parameters or part of the design process,

criteria used did not align with clinically accepted criteria and was unduly influenced by fiscal rationales).

¹⁵ For example, while there is support for the electronic visit verification (EVV) systems for Medicaid home care to ensure people are getting the care they need, there are also concerns about how those systems may place burdens on individuals receiving services and whether if services are not verified, this information will be held against them when services come up for approval.

¹⁶ ¹⁶ See *generally* CMS, Medicaid Eligibility & Enrollment Toolkit, <https://www.medicaid.gov/medicaid/data-systems/medicaid-eligibility-enrollment-toolkit/index.html> (setting forth checklists and performance standards).



how a system will operate is sometimes overlooked. Resulting, for example, in Medicaid eligibility systems that have no function to override a system's decision, or run reports to find people improperly terminated, which sometimes may be due to the person's disability or immigration status.¹⁷ These oversights and errors may result in wrongful termination of health care coverage and the information provided by the system in the notice provided may not be sufficient for a person to identify that the system made an error.¹⁸

In health care, common data sources (claims data; Medicaid expenditures data, etc.) can be particularly bias ridden because of the institutional racism within health care as well as other historical biases.¹⁹ But another factor to consider in health care is that it has historically been a system of austerity—providing only certain amounts of care, which may be determined by a variety of factors including service availability, ability to pay, or policies that dictated what would be provided in a particular treatment setting at that point in time for the population or person in question. This also is a significant source of potential bias as it likely incorporates lack of access to health care and biases in place at that time. In another example, the Medicaid home and community based services (HCBS) system, which provides alternatives to institutional placements, has historically been underfunded, preferred congregate rather than independent settings, and relied on families providing supports and services. ADS that uses historical claims data from this system without making adjustments to current policies will likely identify insufficient resources or recommended services to meet current standards. Such examples show that ADS systems can be biased to provide less care than is actually needed, and likely incorporate lack of access to health care and historical biases.

¹⁷ See, e.g., Nat'l Health L. Program, *A.M.C v. Smith*, <https://healthlaw.org/resource/a-m-c-v-smith-middle-district-of-tennessee/> (summarizing case filed in TN regarding alleged lack of due process and related issues with the eligibility ADS); *Darjee v. Betlach*, <https://healthlaw.org/resource/darjee-v-betlach-united-states-district-court-district-of-arizona/> (summarizing case filed in AZ alleging wrongful termination and denials by eligibility ADS of full Medicaid coverage and related due process issues); Nat'l Health L. Program, *Protections for N.C. Medicaid Beneficiaries: Hawkins v. Cohen*, <https://healthlaw.org/resource/protections-for-n-c-medicaid-beneficiaries-hawkins-v-cohen/> (describing injunction in class action for NC to stop automatic terminations by the State's eligibility ADS without any notice because a worker failed to process the review).

¹⁸ *Id.*; see also Katherine Gregg, *UHIP debacle: R.I. to extend contract, as Deloitte agrees to more concessions*, PROVIDENCE J. (Mar. 15, 2019), <https://www.providencejournal.com/news/20190315/uhip-debacle-ri-to-extend-contract-as-deloitte-agrees-to-more-concessions> (describing years long issues with the Rhode Island Medicaid and SNAP eligibility ADS).

¹⁹ Obermeyer et al., *supra* note 9.



Moreover, health care has historically been a system of austerity – particularly in the area of Home and Community-based Services. Historical claims may be based on common practices of compelling unpaid family supports or setting a standard to provide only enough care to keep people out of an institution, rather than a standard that meets their actual health care needs. This also is a significant source of potential bias as it likely incorporates lack of access to health care and biases in place at that time.

C. Implementation

How an ADS is tested, rolled out, and fully implemented also has decision points that are ripe for bias. For example, if an ADS is piloted, the characteristics of that population can impact the ongoing implementation of the ADS. Also choices made about how can use a health care ADS, instructions on how to use the results of the ADS, and any limitations on its use are all implementation choices that can create bias. Additionally, decisions made how to inform individuals affected by the ADS are particularly relevant to how people are impacted by the system.

D. Current Use of the ADS

Evaluation of sources of bias need to include not only the system itself, but how is it used. For example, is that system currently being used for its intended purposes? If not, has it been adapted and validated for the current use? What about instructions on use of a given system and how to interpret the results? For example, quite a few Medicaid state agencies use the Supports Intensity Scale (SIS) as part of their processes for developing plans of care for people with intellectual/developmental disabilities. The publisher of SIS, AAIDD, says the assessment is used to inform the provision of individualized supports and suggest that any funding formula should not be based on the SIS alone and involve a “satisfactory exceptions process.”²⁰ However, some individuals who have experienced a SIS assessment’s effect on their plans of care would say their experience does not meet that description. In fact, the use of the SIS has been central to several cases challenging the use of an ADS in Medicaid home and community-based services (HCBS) because the application of the SIS assessment tool and accompanying budgeting algorithms were used as hard restrictions, individuals found the

²⁰ AAIDD, Most frequently asked questions about SIS, <https://www.aaid.org/sis/product-information/faqs#.V-FbyWqrKM8>; AAIDD, How Support Needs Can Be Used to Inform the Allocation of Resources and Funding Decisions (Mar. 2018), [supportneeds.pdf \(aaid.org\)](https://www.aaid.org/supportneeds.pdf).



allocation of resources to be too limiting, and exceptions processes were not readily available.²¹ Importantly, the process did not provide sufficient information to affected individuals such that they could challenge the results, thereby violating their constitutional right to due process.²² Advocates in North Carolina have brought multiple cases involving the use of the SIS, with the most recent case claiming that the State's reliance on the SIS fails to take into consideration factors such as available family supports, geographic differences in the costs of services, and other factors and the SIS and its accompanying budget matrix ADS imposed an across-the-board reduction for thousands of individuals, eliminating medically necessary supports.²³

Even today, instructions on how to use the outcome of a SIS assessment differ rather drastically in states.²⁴ In almost all examples of the SIS or similar HCBS assessment tools in Medicaid, the process for choosing the tool, selecting any data needed to apply that tool in a given state, testing application of the tool, and ongoing quality control is not a transparent one. Therefore, it is usually difficult for impacted populations to question whether the tool or any related algorithms are being implemented with fidelity to any recommendations, or if there are potential sources of bias being added to the process or system.

E. Points of Human Interaction with the ADS

²¹ Jane Perkins, Nat'l Health L. Program, *Demanding Ascertainable Standards: Medicaid as a Case Study*, 2016 CLEARINGHOUSE REV. 1 (2016), available at <https://heinonline.org/HOL/LandingPage?handle=hein.journals/clear50&div=8&id=&page=> (describing challenges involving SIS in Idaho and North Carolina, *K.W. v. Armstrong* and *L.S. v. Delia*, respectively, in which the SIS was used to establish a budget for services that individuals could not easily challenge or receive an exception to).

²² *Id.*

²³ Disability Rights NC, *Samantha R. v North Carolina Update* (Feb. 6, 2020), <https://disabilityrightsncc.org/general/samanthar#:~:text=February%206%2C%202020%2C%20Raleigh%2C.people%20with%20disabilities%20from%20discrimination>; see also *Samantha R. v. NC* Complaint at 17-18, <https://disabilityrightsncc.org/wp-content/uploads/2018/06/Samantha-R-Complaint-5-24-17.pdf>.

²⁴ *Compare* NC DHHS, LME-MCO Communication Bulletin J297 (July 13, 2018), <https://files.nc.gov/ncdhhs/Joint-Communication-Bulletin--J297--LME-MCO-LS-V-Wos-Instruction--002-.pdf> (describing using an individual's SIS score as only guidance and one piece of evidence to determine medical necessity of HCBS, never the sole piece of evidence) *with* Iowa DHS, Informational Letter No. 1846-MC-FFS (Nov. 2, 2017), [https://secureapp.dhs.state.ia.us/imp/Information/ViewDocument.aspx?viewdocument=\(3e1564be-4cbf-4bd3-a71c-2c7429136e1b\)](https://secureapp.dhs.state.ia.us/imp/Information/ViewDocument.aspx?viewdocument=(3e1564be-4cbf-4bd3-a71c-2c7429136e1b)) (setting tiered reimbursement rates for services based on an individual's SIS score).



An examination of the sources of human input into an ADS is critical to examination of the system's bias. If the source of input for the system is answers to questions from patients, have those questions been tested for language or cultural variances? When questions are translated to different languages, is the system validated again? Do the questions account for different cultural norms? For example, health care often involves topics that people consider very personal and they may not be comfortable answering questions, even if to a health care provider. How the question is asked and who asks the question can be very relevant. For example, certain cultural norms would likely mean that a person would be uncomfortable honestly answering questions posed by a person of a different gender from them or even if there were significant generational differences.

Another important source of variability and bias is how much, if any, judgment is the interviewer allowed in scoring answers to questions? In the Medicaid HCBS context, interviewer judgment can generate bias in both positive and negative directions.²⁵ For example, if the interview includes a question about whether a person can use the toilet by themselves and the answer is only a "yes/no" a person who cannot ambulate to the toilet independently but instead crawls there may get marked as "totally able" on the assessment, likely resulting in no assistance allocated for that task.²⁶ This may sound hypothetical, but such situations are not unheard of Medicaid ADS assessments. In contrast, if an assessor observes limited mobility and probes further into that question and asks about getting to the toilet, the person would likely be assessed as needing assistance.²⁷ HCBS assessments also typically involve questions about whether a person physically can perform a task, which inherently includes an evaluation of both functional mobility and pain tolerance in a task. However, despite significant research regarding the disparities in evaluation and treatment of pain in Black versus white populations, there has not been significant research or alterations to these assessments to evaluate and control for potential racial bias in these assessment questions or interviewer protocols.²⁸

²⁵ See, e.g., *Weaver v. Colorado Dept. of Soc. Servs.*, 791 P.2d 1230 (Colo. App. 1990) (noting due process concerns when assessment scores are influenced by evaluator subjectivity as opposed to functional improvement of the individual).

²⁶ Machledt, *supra* note 6.

²⁷ *Id.*

²⁸ Janice A Sabin, Am. Assoc. Med. Colleges, *How We Fail Black Patients in Pain* (Jan. 6. 2020), <https://www.aamc.org/news-insights/how-we-fail-black-patients-pain> (summarizing research about disparities in pain evaluation and treatment).



Deference to the individual entering data may also have a significant impact on bias of information going into the system, such as whether that individual is tasked with identify the race, gender, or other identities or characteristics of the individual. This can both skew the data that an ADS may be learning from and it may trigger biases within the system if the individual affected identifies a different way from that perceived by the interviewer.

In instances where an ADS relies on human judgment, robust practices to test routinely for interrater reliability that include analyses to test for implicit bias are absolutely necessary. Adequate training and repetition can help assessors minimize that bias in their work, and the testing is needed to foster trust in the system.

II. Bias in Health Care ADS

Health care has a long history of institutional bias that includes explicit and implicit bias, and has centered the white, heteronormative experience.²⁹ Data collection, research, determinations regarding cause and outcomes, and analyses are all informed by institutional bias within the system.³⁰ Of particular note, recent studies have identified that the research journals, which may often be the starting place of analyses that serve as the basis for ADS, have a significant racial bias.³¹ As discussed earlier, these biases may appear in ADS in ways that are difficult to detect.³²

²⁹ Ibram x. Kendi, *There is No Such Thing as Race in Health-care Algorithms*, 1:8 THE LANCET E375 (Dec. 2019), [https://www.thelancet.com/journals/landig/article/PIIS2589-7500\(19\)30201-8/fulltext](https://www.thelancet.com/journals/landig/article/PIIS2589-7500(19)30201-8/fulltext); Rachel R. Hardeman, Eduardo M. Medina & Katy Kozhimannil, *Structural Racism and Supporting Black Lives—The Role of Health Professionals*, 375 NEW ENG. J. MED. 2113 (Dec. 1, 2016) (summarizing sources of bias in health care);

³⁰ See, e.g., Hannah E Knight et al., *Challenging Racism in the Use of Health Data*, 3:3 THE LANCET E144 (Feb. 3, 2021)(explaining how structural inequalities, biases, and racism in society are easily encoded in datasets and application of data science and how it can reinforce existing injustices and inequalities).

³¹ Rhea Boyd et al., *The World’s Leading Medical Journals Don’t Write About Racism. That’s a Problem*, TIME (Apr. 21, 2021) (finding that the top four medical journals in the world almost never publish scientific articles that name racism as a driver of poor health outcomes and less than 1% of the 200,000 articles published over the past 30 years included “racism” anywhere in the text; of the few articles that did, 90% were predominately opinion pieces); Usha Lee McFarling, *When a Cardiologist Flagged the Lack of Diversity at Premier Medical Journals, the Silence was Telling*, STAT (Apr. 12, 2021), <https://www.statnews.com/2021/04/12/lack-of-diversity-at-premier-medical-journals-jama-nejm/> (discussing the impact on research from the lack of diversity at premier medical journals).

³² *Supra* note 6.



A. Role of Institutional Racism

Health care has well-recognized institutional racism and bias. Although health care ADS are coming under increasing scrutiny, looking to analysis of ADS in other systems with significant institutional bias can be informative as to the pervasive nature of bias, even if the system is tested and termed “race-neutral.”³³ For example, a study found of financial technology (FinTech) companies price mortgages in ways that have a racially discriminatory impact using algorithms. The researchers hypothesize that racial minorities are less likely to comparison shop for mortgages, potentially due to factors such as geography and lack of experience with lending, and the lenders therefore strategically charged them higher prices.³⁴ According to one co-author, “[t]he mode of lending discrimination has shifted from human bias to algorithmic bias... Even if the people writing the algorithms intend to create a fair system, their programming is having a disparate impact on minority borrowers—in other words, discriminating under the law.”³⁵ In the criminal justice context, the risk assessment instrument COMPAS, which does not take race or ethnicity as an input, disproportionately and incorrectly labels Black individuals as highly likely to commit future crimes, thereby resulting in longer

³³ See, e.g., Mikella Hurley & Julius Adebayo, *Credit Scoring in the Era of Big Data*, 18 YALE J. L. & TECH. 148 (2016), <https://digitalcommons.law.yale.edu/cgi/viewcontent.cgi?article=1122&context=yjolt> (describing how AI may combine facially neutral data and use them as proxies for immutable characteristics that may be protected classes, other issues of discrimination in algorithms, and the problems related to transparency); see also Rose Eveleth, *Credit Scores Could Soon Get Even Creepier and More Biased*, VICE NEWS (Jun. 13, 2019), https://www.vice.com/en_us/article/zmpgp9/credit-scores-could-soon-get-even-creepier-and-more-biased (highlighting how artificial intelligence used to create credit scores can unintentionally reflect bias and transparency issues related to such algorithms); Jordan Pearson, *AI Could Resurrect a Racist Housing Policy*, VICE NEWS (Feb. 2, 2017), https://www.vice.com/en_us/article/4x44dp/ai-could-resurrect-a-racist-housing-policy (discussing algorithmic redlining and transparency problems with algorithmic decision making); see also VIRGINIA EUBANKS, *AUTOMATING INEQUALITY* (2018); A.I. Now Institute, *Litigating Algorithms* 8 (2018), <https://ainowinstitute.org/litigatingalgorithms.pdf>; A.I. Now Institute, *Litigating Algorithms 2019 US Report: New Challenges to Government Use of Algorithmic Decision Systems* (2019), <https://ainowinstitute.org/litigatingalgorithms-2019-us.pdf>.

³⁴ Robert Bartlet et al., *Consumer-Lending Discrimination in the FinTech Era* 5 (2019), <http://faculty.haas.berkeley.edu/morse/research/papers/discrim.pdf>.

³⁵ Laura Counts, *Minority homebuyers face widespread statistical lending discrimination, study finds*, (Nov. 13, 2018) <https://newsroom.haas.berkeley.edu/minority-homebuyers-face-widespread-statistical-lending-discrimination-study-finds/>.



prison sentences and harsher terms.³⁶ In both of these examples, the exact source of bias in these systems may not be able to be pinpointed or corrected for as it is likely the impact of bias throughout the system from data sampling to design to how the input interacts. Given the pervasiveness of bias in health care and the role of social determinants of health, it is likely that in health care we should assume there is racial bias in health care and try to protect against how such biases impact individuals.

B. Disability & Age

People with disabilities consistently face bias in health care tools. Long-standing and ongoing bias about the quality of life for a person with a disability impacts their ability to access health care. In addition, people with disabilities often face the use of tools that, while they may be complex, often do not fully take into consideration the unique combination of that individual's needs.

One of the most common tools often built into systems that measure clinical cost-effectiveness, known as quality-adjusted life years (QALYs), unfairly discriminates against people with disabilities by undervaluing their quality of life. The principle source of this discrimination is that QALYs depend on asking people without disabilities to put a value on the experience of living with a disability, for which they often have no point of reference. QALYs have long been opposed by people with disabilities and disability rights advocates.³⁷ Use of QALYs tends to undervalue vital treatments that extend or improve the lives of people with disabilities. This is because QALYs reduce the value of treatments that do not bring a person back to a definition of "healthy" and "functioning" that do not account for the complexity of patient experiences.

People with disabilities consistently face bias in health care tools. Long-standing bias about the quality of life for a person with a disability impacts their ability to access health care. Clinical tools often assume that having a disability means the person has a lower quality of life or it is somehow less valuable than that of a person without a disability. This measurement and related assumptions, known as quality-adjusted life years (QALYs) has long been opposed by people

³⁶ Julie Angwin et al, *Machine Bias*, ProPublica (2016), <https://www.propublica.org/article/machine-bias-risk-assessments-in-criminal-sentencing>.

³⁷ See, e.g., National Council on Disability, *Quality Adjusted Life Years and the Devaluation of Life with Disability* (Nov. 6, 2019), https://ncd.gov/sites/default/files/NCD_Quality_Adjusted_Life_Report_508.pdf.



with disabilities and disability rights advocacy.³⁸ Use of QALYs tends to undervalue vital treatments that extend or improve the lives of people with disabilities. This is because QALYs reduce the value of treatments that do not bring a person back to a definition of “healthy” and “functioning” that do not account for the complexity of patient experiences. Although QALYs appear in a number of health care ADS, the impact of QALYs was forced into the spotlight by many of the policies around COVID-19 health care rationing. Advocacy regarding plans for health care rationing identified protocols, including some that relied on ADS, that illegally discriminated against people with disabilities and older adults.³⁹ Complaints to HHS Office of Civil Rights resulted in settlements and HHS guidance that people with disabilities “should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person’s relative ‘worth’ based on the presence or absence of disabilities or age.”⁴⁰ State COVID-19 vaccine allocation systems also highlighted ways in which people with disabilities and other protected classes were denied equal access through health care prioritization and automated systems that failed to take into consideration barriers to access.⁴¹

1. Bias Within Disability-Specific ADS

Even within health care ADS targeted to people with disabilities and assessments of function and needs, disability bias occurs. Certain HCBS assessments, including those intended to be comprehensive, have received criticism for failing to adequately account for cognitive disabilities that may impact an individual’s need for community-based services.⁴²

Measuring cognitive function can be especially challenging for conditions like brain injuries that commonly impact higher level cognitive abilities, such as executive decision-making and attention. Such conditions might confound assessment results because they may manifest

³⁸ See, e.g., National Council on Disability, Quality Adjusted Life Years and the Devaluation of Life with Disability (Nov. 6, 2019), https://ncd.gov/sites/default/files/NCD_Quality_Adjusted_Life_Report_508.pdf.

³⁹ See generally Ctr. for Public Representation, COVID-19 Medical Rationing & Facility Visitation Policies, [COVID-19 Medical Rationing & Facility Visitation Policies – Center for Public Representation](#).

⁴⁰ U.S. Health & Hum. Servs. Office for Civil Rights, Bulletin: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19) (Mar. 28, 2020), [ocr-bulletin-3-28-20.pdf \(hhs.gov\)](#).

⁴¹ See Cathren Cohen, Nat’l Health L. Program, [To End the Pandemic, California Must Prioritize Equity in Vaccine Distribution - National Health Law Program](#) (Feb. 15, 2021); Hannah Eichner, Nat’l Health L. Program, [The Time is Now to Vaccinate High-Risk People with Disabilities - National Health Law Program](#) (Mar. 15, 2021); see generally Ctr. for Public Representation, Vaccine Allocation, [Vaccine Allocation – Protect Our Medicaid \(publicrep.org\)](#).

⁴² See *supra* note 6.



intermittently (and, thus, outside the window of the assessment).⁴³ Moreover, people with brain injuries often overestimate their own functional abilities during assessments.⁴⁴ The State of New York acknowledged these problems, twice delaying transition to a uniform assessment tool for the state's Traumatic Brain Injury waiver because the new tool scored many existing waiver recipients below an institutional Level of Care, rendering them ineligible.⁴⁵

In addition, advocates in several states have identified HCBS ADS that fail to properly factor in how a diagnosis of cerebral palsy affects a need for services, causing people with that diagnosis to either be approved for a far fewer services than they should have or to lose eligibility for critically important programs.⁴⁶ Such outliers or oversights are common in HCBS tools. One study of four state assessment systems found that overall, the tools only identified between 24% to 37% of the highest cost users.⁴⁷

HCBS ADS have also demonstrated other sources of bias, including toward certain care settings.⁴⁸ One common problem is the bias towards congregate or disability-specific settings, which contravenes a person with a disability's right to live in the most integrated setting appropriate to their needs.⁴⁹ Most HCBS ADS are calibrated with historical use data.

⁴³ A longer lookback period can also make it more difficult to accurately calculate how much assistance has been provided.

⁴⁴ *Medicaid Balancing Incentive Program: Recommendations for Core Assessment Tools for Individuals with Brain Injury*, NAT'L ASS'N OF STATE HEAD INJURY ADM'RS 7 (June 2015), https://www.nashia.org/pdf/sos2015/presentations/nashia-csa-recommendations_revised_june_2015.pdf.

⁴⁵ People with serious mental illnesses sometimes encounter analogous problems with Level of Care if their symptoms manifest more sporadically.

⁴⁶ See, e.g., Colin Lecher, *What Happens When an Algorithm Cuts Your Health Care*, THE VERGE (Mar. 21, 2018), <https://www.theverge.com/2018/3/21/17144260/healthcare-medicaid-algorithm-arkansas-cerebral-palsy>. Advocates in other states have identified programming errors that led to ADS terminating eligible individuals with cerebral palsy from Medicaid HCBS waiver program or failed to consider people with the condition to meet the definition of having a developmental disability even though the state definition included those individuals.

⁴⁷ Brant E. Fries et al., *Increasing Access to Home and Community Based Services through Equitable Resource Allocation Methodologies: Final Project Report*, UNIV. MICH. 18 (June 2015).

⁴⁸ See generally Machledt, *supra* note 6.

⁴⁹ *Olmstead v. L.C. ex rel Zimring*, 527 U.S. 581 (1999) (holding that "unjustified institutional isolation of persons with disabilities is a form of discrimination"); Home and Community-Based Setting Requirements for Community First Choice and Home and Community-Based Services (HCBS) Waivers, 79 Fed. Reg. 2948, 3011 (Jan. 16, 2014) (to be codified at 42 C.F.R. pts. 430, 431, 435, 436, 440, 441 & 447).



Unfortunately, HCBS have been chronically underfunded. An ADS that allocates HCBS resources cannot cure underfunding – it only redistributes inadequate resources.⁵⁰

State HCBS programs have also historically favored group based settings for services, both residential and day activities, including employment.⁵¹ In West Virginia, advocates alleged that the HCBS ADS resulted in greater funding for individuals who lived in provider-operated residential settings compared to individuals who opted to live independently or with family.⁵² Such a funding preference potentially creates a bias towards greater segregation from the community, in violation of the individuals' civil rights. Medicaid HCBS ADS may also incorporate bias towards institutional rather than community placement, in violation of the community integration mandate of the ADA.⁵³ HCBS ADS have also allegedly been used to violate the ADA's community integration mandate by making across the board cuts, which may threaten people's ability to live in the community instead of an institution.⁵⁴

Our analysis of HCBS ADS suggest they may be confounded by the amount of unpaid supports from family members when a person lives in a family home versus a provider-operated residential setting.⁵⁵ Most HCBS ADS are based on data and service usage (and related analyses) prior to changes to the Medicaid HCBS rules that included new prohibitions against compelling unpaid supports in determining the services a person needed, and these

⁵⁰ Mary L. James et al., Design Principles for HCBS Case Mix: A Primer, UNIV. OF MICH. INST. OF GERONTOLOGY, 6 (June 2015),

<http://www.nasuad.org/sites/nasuad/files/HCBS%20Case%20Mix%20Primer.pdf>.

⁵¹ See, e.g., *Steimel v. Wernert*, 823 F.3d 902 (7th Cir. 2016) (finding segregation from the community can occur through lack of services); *Murphy by Murphy v. Harpstead*, 421 F. Supp. 3d 695 (D. Minn. 2019) (discussing the right to live in the most integrated setting); *Lane v. Brown*, 166 F. Supp. 3d 1180 (D. Or. 2016) (addressing segregated employment as discrimination); HCBS Rule, *supra* note 49.

⁵² *Michael T. v. Crouch*, 344 F. Supp. 3d 856 (S.D.W.V. 2018).

⁵³ See, e.g., *Pashby v. Cansler*, 279 F.R.D. 347 (E.D.N.C. 2011). The decision in *Pashby* did not directly address the use of the assessment tool, but an assessment tool was part of the finding that the in-home population was treated differently than the facility-based population, in violation of comparability.

⁵⁴ See, e.g., Disability Rights Oregon, Lawsuit: Protecting In-Home Care Hours, <https://www.droregon.org/litigation-resources/cs-v-odhs> (describing challenging to Medicaid HCBS ADS and due process issues, for more detailed information see the link to the FAQ: Analysis of Legal Issues); *K.W. v. Armstrong*, 789 F.3d 962 (9th Cir. 2015).

⁵⁵ See, e.g., 42 C.F.R. § 441.301(c)(2)(v) (natural supports must be provided voluntarily in lieu of paid supports); see also *Waskul v. Washtenaw Cnty. Cmty. Mental Health*, 979 F.3d 426, 451-52 (6th Cir. 2020) (discussing plaintiffs' argument that the assessment of need and budgeting process inappropriately assumes availability of natural supports).



services are not represented in claims data used by ADS.⁵⁶ Very few, if any, of these tools and ADS were updated to reflect the HCBS rule changes, which also made clear that people must have the option of non-disability specific settings for their services. HCBS ADS are more likely to be designed to indicate individuals' needs can be met in group settings rather than in more independent, integrated settings.

HCBS ADS have also incorporated bias from state policies or from the underlying analysis for the ADS. In Washington, several cases involving the CARES tool successfully challenged how the tool decreased benefits by 15 percent if an individual lived with a paid caregiver regardless of whether the person was available during non-paid hours and how the tool automatically reduced services based on a child's age without evidence of decreasing need.⁵⁷ In Florida, litigation challenged the HCBS ADS and its alleged fundamental flaws, including a consistently underestimated services budget. After dueling expert testimony, the judge acknowledged the difficulty in navigating the budgetary process, including the ADS, but ultimately found the plaintiffs had not proven that they would lose funding.⁵⁸

Children with disabilities are uniquely impacted by health care ADS. Health care ADS are often based originally on adults and then "normed" to children. This process may fail to account for the unique aspects of children's health, especially when they have disabilities. Depending on the process used to apply a health care ADS to children, there may be compounding racial bias if it did not fully take into consideration how children of color experience chronic health conditions in children at a higher rate than white children, and other health issues more prevalent in children of color.⁵⁹ These health disparities were highlighted by the impact of COVID-19 on Black and Latino children disproportionately representing recorded cases and

⁵⁶ *Id.*

⁵⁷ *Jenkins v. Washington State Department of Social and Health Services*, 160 Wash. 2d 287, 299 (Wash. 2007); *Samantha A. v. Department of Social and Health Services*, 171 Wash. 2d 623 (Wash. 2011) (finding that the tool's automatic reduction in personal care services based on the child's age and whether the child was living with their legally responsible parent violated comparability). When a state makes across the board cuts through an HCBS ADS it is unclear whether such changes affect the validity of the tool itself, which may be another source of bias.

⁵⁸ *Brandy C. v. Palmer*, No. 4:17-CV-226, 2018 WL 4689464 (N.D. Fla. Sept. 29, 2018); see also *S.D. v. Saiki*, No. 6:17-CV-00770, 2018 WL 7108063 (D. Or. Oct. 11, 2018) (dismissing plaintiff's claims challenging the validity of an HCBS assessment tool).

⁵⁹ See, e.g., Sofia Carratala & Connor Maxwell, *Health Disparities by Race and Ethnicity* (May 9, 2020), <https://www.americanprogress.org/issues/race/reports/2020/05/07/484742/health-disparities-race-ethnicity/> (summarizing health disparities statistics).



deaths.⁶⁰ Race also has an impact on end of life care for medically complex children.⁶¹ The extent to which the process of norming ADS for children's health should be closely examined for bias.

Sometimes, the states do not meaningfully norm a tool to its population. We have heard reports of state Medicaid agencies adopting tools from other states and applying them to a different purpose or making changes to the HCBS ADS without evaluating how the changes might affect the validity of the tools. Several years ago, a state changed its assessment tool for personal care services for children. According to advocate reports, the new tool was minimally adapted from Wisconsin's functional Level of Care screen for children, which is designed as an eligibility screen. The state in question wanted to use it to allocate resources, but information available indicated it did little to validate if this purpose was appropriate.

Although all children should receive services that are medically necessary, how medical necessity is defined may be different in different ADS. There may be bias in this determination or definition. This is particularly relevant for children who use Medicaid as they are required by law to receive all medically necessary services to correct or ameliorate their condition, regardless of whether a state provides those services for adults or limits those services.⁶² A health care ADS may be based on insurance standards or a measure that is inherently based in cost-saving measures and thus illegally limit a Medicaid child's access to services. While the Medicaid requirement for children is not limitless, there have been repeated instances of health care utilization tools not factoring in the Medicaid requirements even when used on Medicaid children.⁶³

⁶⁰ See, e.g., Arielle Mitropoulos, ABC News, Children of Color Disproportionately impacted by severe COVID-19 and related illness, data reveals (Feb. 25, 2021), <https://abcnews.go.com/Health/children-color-disproportionately-impacted-covid-19-data-reveals/story?id=76063845>.

⁶¹ Renee D. Boss, *Social Disparities and Death Among Children with Complex Chronic Conditions*, 143 PEDIATRICS 143 (May 2019), <https://pediatrics.aappublications.org/content/143/5/e20190511>; Maria Trent, Danielle G. Dooley, Jacqueline Dougé, *The Impact of Racism on Child and Adolescent Health*, 144(2) PEDIATRICS e20191765 (Aug. 2019),

<https://pediatrics.aappublications.org/content/144/2/e20191765> (discussing the importance of acknowledging the role of racism in child and adolescent health).

⁶² 42 U.S.C. §§ 1396a(a)(10)(A), 1396a(a)(43), 1396d(a)(4)(B), 1396d(r)(5); see generally CMS, EPSDT—A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents (June 2014), https://www.medicaid.gov/sites/default/files/2019-12/epsdt_coverage_guide.pdf.

⁶³ Salazar, 596 F.Supp.2d 67; *Samantha A.*, 171 Wash. 2d 623 (finding that the tool's automatic reduction in personal care services based on the child's age and whether the child was living with their legally responsible parent violated Medicaid comparability) see also *M.H. v. Berry*, No. 1:15-CV-1427,



Bias towards people with disabilities is also at the heart of requirements that mental health and substance use disorder services be provided in parity with medical and surgical services. For decades Congress has enacted legislation trying to end bias in insurance coverage, clinical criteria, benefit design, and utilization management that limits access to medically necessary services.⁶⁴ Over time, the more straightforward quantitative parity violations, such as limits on office visits, have been resolved leaving the more complex non-quantitative treatment limitations (NQTLs) that are often tied to clinical guidelines and processes. While health care ADS is not always at play in parity issues, clinical criteria and utilization management functions often include ADS. Parity requirements under ERISA require disclosure of not only general policies, but more specific information about the underlying decisions, processes, strategies, evidentiary standards, and other factors used with respect to mental health/substance use disorder services and medical/surgical services upon request and free of charge.⁶⁵ Importantly, plans and issuers cannot refuse disclosure of such information based on claims of commercial value.⁶⁶ However, disclosure with sufficient transparency to evaluate potential parity violations or other sources of bias has proven incredibly difficult and has been a major barrier to parity compliance.⁶⁷ As AHRQ considers how to improve evaluation of bias and the transparency likely required, it should consider how the disclosure requirements have worked in mental health parity compliance.

2. Failure to Consider Disability May Contribute to Sources of Bias

For HCBS ADS the person using the results, such as those facilitating person-centered planning, can also be a significant source of bias. Medicaid regulations have conflict of interest standards that prevent certain parties from participating in the person-centered planning

2021 WL 1192938 (N.D. Ga. Mar. 29, 2021) (challenging the use of an assessment tool denying children's medically necessary nursing services, including an allegation the tool had not been scientifically validated).

⁶⁴ For a history of mental health parity, see Elizabeth Edwards & Abigail Coursolle, [Mental Health Parity: Disclosure of information is necessary says NHeLP in friend of the court brief](#) (Nov. 17, 2020) and linked amicus brief in *N.R. v. Raytheon*.

⁶⁵ U.S. Dept. of Labor, Self-Compliance Tool for the Mental Health Parity and Addiction Equity Act (MHPAEA) Tool 28-30, <https://www.dol.gov/sites/dolgov/files/EBSA/laws-and-regulations/laws/mental-health-parity/self-compliance-tool.pdf>.

⁶⁶ *Id.* at 30.

⁶⁷ See Abigail Coursolle & Elizabeth Edwards, Nat'l Health L. Program, [Mental Health Parity: Substance Use Disorder](#) (Nov. 17, 2020).



process that typically uses HCBS ADS outcomes to plan the HCBS a person will receive to meet their needs. But these standards do not prohibit Medicaid managed care plan care coordinators from facilitating this process.⁶⁸ The care coordinator may, and often does, work for the same organization that approves and denies services and typically has a financial interest in denying services. Typically, a firewall is required between a plan's utilization management side and care coordinators who facilitate person-centered planning and often administer HCBS ADS assessments. In practice though, this division can be quite blurry. Many individuals with disabilities feel discouraged during the planning process from asking for the services they need that may be outside their HCBS ADS results. In NC, litigation related to the State's practices around the use of the SIS resulted in specific guidance aimed at preventing inappropriate reliance on the HCBS ADS, and thus inappropriate denials of medically necessary care.⁶⁹

Health care ADS also often fail to take into consideration that a person with a disability may need a reasonable modification to a policy or procedure in order to enjoy equal access to the health care service in question, as required by non-discrimination requirements.⁷⁰ For example a person with a cognitive disability may require more visits with a mental health professional to achieve the same benefit as people without a cognitive disability. Or a person with a pre-existing physical disability may need additional physical therapy sessions to rehabilitate an injury. This becomes more complicated when an individual has multiple or complex disabilities for which an ADS may have particular difficulty detecting and making necessary adjustments. Even ADS focused on determining services for people with disabilities often fail to fully account for the wide array of disabilities and needs a person may have.

Broadly speaking, HCBS ADS are relatively imprecise modeling tools. Widely cited validations of InterRai's RUG-III/HC algorithm, one of the most commonly used ADS, showed that model accounted for 34% to 37% of the actual sample variation.⁷¹ Experts consider these validations acceptable; the RUG-III/HC adequately sorts people into similar groups with similar resource patterns. But that leaves a lot of variation unaccounted for by the model – ranging from the amount of informal care received to regional differences in provider costs or availability to

⁶⁸ 42 C.F.R. § 441.301(c)(1)(v)-(vi); 42 C.F.R. § 441.730(b).

⁶⁹ See NC DHHS, LME-MCO Communication Bulletin, *supra* note 24.

⁷⁰ 42 U.S.C. § 12132; 29 U.S.C. § 794; 42 U.S.C. § 18116.

⁷¹ Magnus A. Björkgren, *A RUG-III Case-Mix System for Home Care*, 19 suppl. 2 CANADIAN J. ON AGING 106 (2000); Jeffrey W. Poss, et al., *Validation of Resource Utilization Groups Version II for Home Care (RUG-II/HC): Evidence from a Canadian Home Care Jurisdiction*, 46 MED. CARE 380 (2008).



health conditions that may not have been measured. In general, the ADS work best at a population level. The HCBS ADS remain relatively imprecise, at least when applied to an individual's unique context, and should be approached with statistical humility. This is why any individual budgeting should include mechanisms to reassess and, if necessary, adjust individual budgets. This could include having the assessment point to a range of dollars or hours rather than a single figure. Implementing a clear exceptions process is also important, especially to identify outliers that the assessment process missed.

Unfortunately, many ADS do not have readily available exceptions processes. This is especially important for people with disabilities who may need an exception to be granted as a reasonable modification so that they much have equal access to services. Also, since the ADS often fail to recognize outliers for a variety of reasons, the exceptions process may be the only way such individuals can access the care they need.⁷² When an ADS is used, a person should always be informed of an available exceptions process that is easy to navigate and has clear criteria for being granted an exception. Without such a process, individuals impacted by ADS cannot raise their hand to indicate bias in the system.

Health care ADS that relies on patient data input may also fail to accommodate individual access needs for people with disabilities. For example, if the system relies on individuals providing information through an application or web portal, is that system fully accessible to all people with disabilities? Including people with disabilities with communication needs? Who are blind or have low vision? Who have cognitive disabilities? Do such systems undermine personal autonomy and privacy of health information of a person with a disability by relying on a third-party mechanism for inputting data? Such methods may also violate non-discrimination provisions by not providing equal access to the program. Health care ADS that rely on patient input may have other sources of bias due to the lack of internet access and computer or smartphone ownership.⁷³ People with lower incomes, older adults, and people of color are

⁷² See, e.g., *Belancio v. Kansas Dept of Health and Environment*, No. 17-CV-1180, 2018 WL 4538451 (D. Kan. Sept. 21, 2018) (finding an individual's requested reasonable modification to the State's assessment and budgeting process, and related policies, was appropriate based on their identified needs).

⁷³ Monica Anderson & Madhumitha Kumar, *Digital Divide Persists Even as Lower-Income Americans Make Gains in Tech Adoption*, PEW RES. CTR.: FACTTANK, May 7, 2019, <https://www.pewresearch.org/fact-tank/2019/05/07/digital-divide-persists-even-as-lower-income-americans-make-gains-in-tech-adoption/> (nearly one-third of low-income Americans rely on smartphones with data plans for internet access, but roughly three-in-ten adults in lower income

more likely to experience the three most common barriers to telehealth usage: absence of technology, digital literacy, and reliable internet; a combination known as the “digital divide.”⁷⁴ The lack of reliable and affordable internet has been tied to economic development, but also to digital red-lining and the lack of infrastructure linked to institutional racism.⁷⁵ This impacts access for certain populations, including people with disabilities to use certain ADS input mechanisms. For example, certain applications used for remote monitoring, as related to telehealth programs, may not be fully accessible or people with disabilities may not have access to the technology necessary to use those applications.⁷⁶ When evaluating bias in an ADS, the whole process related to use of ADS must be examined.

households do not own a smartphone). In addition to not many adults in lower-income households owning a smartphone, a similar percentage of such adults (26%) are smartphone dependent internet users in that they own a smartphone, but do not have internet access at home. *Id.* In addition, more than 30% of Latinx or Black children have no computer at home, more than twice the rate for white children (14%). David Velasquez & Ateev Mehrotra, *Ensuring the Growth of Telehealth During COVID-19 Does Not Exacerbate Disparities in Care*, HEALTH AFFAIRS

BLOG (2020), <https://www.healthaffairs.org/doi/10.1377/hblog20200505.591306/full/> (finding that digital literacy is much lower for older people of color and for people with less education).

⁷⁴ David Velasquez & Ateev Mehrotra, *supra* note 7373; see also Michelle W. Katzow, Caren Steinway & Sophia Jan, *Telemedicine and Health Disparities During COVID-19*, 146 PEDIATRICS (2020) (finding that lower-income adults are less likely to have access to a computer or to use email as well as highlighting the need for alternative platforms for telemedicine such as applications like Whatsapp).

⁷⁵ See *On the Wrong Side of the Digital Divide*, GREENLINING (June 2, 2020), https://greenlining.org/publications/online-resources/2020/on-the-wrong-side-of-the-digital-divide/?utm_source=sendgrid&utm_medium=email&utm_campaign=Newsletters (drawing the connection through mapping between access to the internet and redlining); Betsy Lawton, *Assessing Efforts to Ensure Equitable Access to Broadband Services that Support Public Health*, NETWORK FOR PUBLIC HEALTH LAW (Oct. 8, 2020), <https://www.networkforphl.org/news-insights/assessing-efforts-to-ensure-equitable-access-to-broadband-services-that-support-public-health/> (discussing digital redlining and racial disparities in access to broadband); see, e.g., Bill Callahan, *AT&T's Digital Redlining of Dallas: New Research by Dr. Brian Whitacre*, Nat'l Digital Inclusion Alliance (Aug. 6, 2019), <https://www.digitalinclusion.org/blog/2019/08/06/atts-digital-redlining-of-dallas-new-research-by-dr-brian-whitacre/> (finding that AT&T withheld fiber-enhanced broadband improvements from most Dallas neighborhood with high poverty rates, relegating them to vastly inferior internet access services compared to other areas of Dallas); see also Nicole Dozier & William H. Munn, *Historical Geography and Health Equity*, 81(3) N.C. MED. J. 198 (May 4, 2020), <https://www.ncmedicaljournal.com/content/ncm/81/3/198.full.pdf> (drawing connections between present day sociohealth outcomes, including a discussion of infrastructure, and the prevalence of slavery in North Carolina).

⁷⁶ Thiru M. Annaswamy, Monica Verduzco-Gutierrez & Lex Frieden, *Telemedicine Barriers and Challenges for Persons with Disabilities: COVID-19 and beyond*, 13 DISABILITY HEALTH J. 1-2 (July 9, 2020), available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7346769/pdf/main.pdf>. For example,



C. LGBTQ & Intersectionality

Currently, many algorithms that exist in our health care system ask about sex and gender by way of using a binary question: is a patient “male” or “female”?⁷⁷ Binary sex-based data inherently buries information about the patients on the other side of the computer screen. Lesbian, Gay, Bisexual, Transgender, and Queer populations, especially transgender and non-binary individuals, are harmed disproportionately.⁷⁸ This is because one’s sex assigned at birth does not convey one’s gender identity, sexual orientation, race, and additional factors that capture complex lived experiences. In addition, even with comprehensive legal protections, transgender and non-binary people are one of the most medically underserved populations in the U.S.⁷⁹ Without intentional efforts to create and improve algorithms that encompass more intersectional factors of sexual and gender identity and behaviors, the health care system misses the opportunity to catch disparities and, thus, build a more equitable health system.⁸⁰

First, while there is a lot of information about the ways in which LGBTQ people face certain health disparities, there is no consensus that this data *should* be collected and as to how best to collect the data on a broader scale.⁸¹ Abysmal amounts of detailed data about LGBTQ

some people with intellectual disabilities may have difficulty with effective communication through telehealth and people with mobility or manual dexterity disabilities may experience problems with the virtual interface or device. *Id.*

⁷⁷ Madeline B. Deutsch, et al., *Electronic Health Records and Transgender Patients—Practical Recommendations for the Collection of Gender Identity Data*, *Journal of General Internal Medicine*, (2014), <https://link.springer.com/content/pdf/10.1007/s11606-014-3148-7.pdf>.

⁷⁸ S.E. James, et al., Nat’l Ctr. for Transgender Equality, *The Report of the 2015 U.S. Transgender Survey*, (2016), <https://www.transequality.org/sites/default/files/docs/USTS-Full-Report-FINAL.PDF>.

⁷⁹ Wyatt Koma, et al., Kaiser Family Foundation, *Demographics, Insurance Coverage, and Access to Care Among Transgender Adults* (Oct. 21, 2020), <https://www.kff.org/health-reform/issue-brief/demographics-insurance-coverage-and-access-to-care-among-transgender-adults/>.

⁸⁰ Jason Hiner, *Why tech made racial injustice worse, and how to fix it*, C-Net (June 25, 2020), <https://www.cnet.com/news/why-tech-made-racial-injustice-worse-and-how-to-fix-it/>.; See also Amanda Lenhart, et al., *Good Intentions, Bad Inventions: The Four Myths of Healthy Tech*, *Data & Society* (Oct 2020), <https://datasociety.net/wp-content/uploads/2020/10/Healthy-Tech-Myths-DataSociety-20201007.pdf>.; See also Sara Harrison, *Five Years of Tech Diversity Reports –and Little Progress* (Oct. 1, 2019), <https://www.wired.com/story/five-years-tech-diversity-reports-little-progress/>. The field of technology is notoriously represented by white, cisgender males and the narrow representation leads to projecting biases on marginalized populations through algorithms. Failure to fully understand how algorithms function in practice often results in unintended harm because of the lack of representation in the course of their creation.

⁸¹ *Id.*



people still remains as one of the largest barriers to learning about such a diverse umbrella of populations, especially communities of color within.⁸² The concepts of “sex”, “gender”, and “sexual orientation” are still heavily conflated.⁸³ Despite attempts to learn more about LGBTQ populations, inconsistent participation and execution reinforces sporadic data and invisibility of the unique experiences within the broad LGBTQ population, who are often lower-income and on Medicaid. For example, studies frequently report about “LGBT populations” yet fail to disaggregate the data within such populations. It is a missed opportunity to develop enriched data considering cisgender LGB populations and Transgender populations face unique barriers, many of which are perpetrated by members within the LGBTQ population like racism and transphobia. The resulting data produces more questions than it answers and dilutes understanding of this diverse population of people. The absence of broader consensus, buy-in, and investment in tackling LGBTQ health disparities continues to undercut the potential of algorithms and other technology.⁸⁴

Existing algorithms and data collection remain deeply flawed. Algorithms like facial recognition technology, sexual orientation and gender identity (SOGI) data collection, laboratory or diagnostic testing, or inconsistencies in electronic health records (EHRs) alienate LGBTQ individuals and miss key information resulting in underdiagnoses of serious health conditions, such as cancer, substance use, or HIV/AIDS.⁸⁵

⁸² Samuel N. Dubin, et al., *Transgender health care: improving medical students’ and residents’ training and awareness*, *Advances in Medical Education and Practice*, NAT’L CTR. FOR BIOTECHNOLOGY INFORMATION (2018), <https://pubmed.ncbi.nlm.nih.gov/29849472/>.

⁸³ Taylor M. Cruz, *Perils of data-driven equity: Safety-net care and big data’s elusive grasp on health inequality*, *Big Data & Society – SAGE Journals*, (2020), <https://journals.sagepub.com/doi/full/10.1177/2053951720928097>.

⁸⁴ *Id.*

⁸⁵ Matthew B. Shabath, et al., *Ask and Tell: The Importance of the Collection of Sexual Orientation and Gender Identity Data to Improve the Quality of Cancer Care for Sexual and Gender Minorities*, *Journal of Oncology Practice*, Vol. 13, Issue 8 (August 2017), <https://ascopubs.org/doi/full/10.1200/JOP.2017.024281>.; See also Laleh Seyyed-Kalantari, et al., *Medical imaging algorithms exacerbate biases in underdiagnosis*, Univ. of Toronto (Posted Feb 4, 2021), <https://www.researchsquare.com/article/rs-151985/v1>.; S.E. James, *supra*, note 78; See also Taylor M. Cruz *supra*, note 8383; see also, Foad Hamidi, et al., *Gender Recognition or Gender Reductionism? The Social Implications of Automatic Gender Recognition Systems*, *CHI Human Factors in Computing Systems* (April 2018), <https://dl.acm.org/doi/10.1145/3173574.3173582>. Facial recognition technology often leads to invasive and faulty categorization based on misguided algorithms rooted in racist, binary, essentialist computing. The harm this causes is the violent policing of people’s bodies, especially the bodies of Black and gender non-conforming people.

In the context of Medicare and Medicaid, transgender and non-binary individuals are caught at the crosshairs of harmful algorithms with gender/procedure “conflict” errors.⁸⁶ CMS and SSA, as examples, still only collect the antiquated binary “sex” options of male or female in applications and do not disaggregate or collect in a systematic way, despite increased visibility in gender diversity.⁸⁷ To date, transgender and non-binary Medicare beneficiaries are not asked about their gender identity and changes to gender markers are not tracked.⁸⁸ Historically, Medicare could (and would) deny a myriad of health services if the gender marker in the system did not “match” the perceived gender-related procedure.⁸⁹ Medicaid managed care plans in states with strong legal protections for gender-diverse populations still systematically deny gender-affirming care to transgender beneficiaries, but this type of data is not consistently tracked.

While code workarounds have sought to eliminate health service denials based on “gender conflicts” for transgender beneficiaries, many limitations remain. In 2015, CMS adopted the 10th Revision of the International Classification of Diseases (ICD-10), which contains certain changes to transgender-specific ICD codes for including diagnosis codes in medical claims to CMS. In addition, CMS instructed such claims include one of two billing modifiers, condition code 45 and the KX modifier to avoid gender/procedure “conflicts”.⁹⁰

The above coding workarounds only capture transgender people diagnosed with “gender identity disorder” or who have sought gender-affirming medical services, but not those who do not wish to, or cannot, undergo such services.⁹¹ The two billing modifiers apply to more diagnoses and billing multiple services beyond just transgender-related care services.⁹² In

⁸⁶ Erin R. Ewald, ScM et al., *Identifying Medicare Beneficiaries Accessing Transgender-Related Care in the Era of ICD-10* (Nov. 4, 2019), https://www.researchgate.net/publication/333098238_Identifying_Medicare_Beneficiaries_Accessing_Transgender-Related_Care_in_the_Era_of_ICD-10; see also Kimberly Proctor et al., *Identifying the Transgender Population in the Medicare Program* (Dec 1, 2016), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5367475/>.

⁸⁷ *Id.*, Currently, approximately 20 states legally recognize non-binary or third gender markers. See Nat’l Ctr. for Transgender Equality, Identity Documents Center, <https://transequality.org/documents>.

⁸⁸ *Id.*

⁸⁹ *Id.*, For example, if a transgender male’s gender marker is indicated M and seeks a pelvic examination, the claim might trigger a “mismatch” based on the gender and the procedure.

⁹⁰ *Id.*

⁹¹ *Id.*; The *Diagnostic and Statistical Manual of Mental Disorders*, Fifth Edition changed “gender identity disorder” to “gender dysphoria” to shift from a disease framework to an identity framework. The ICD-10 codes still reflect the DSM, Fourth Edition.

⁹² *Id.*



addition, utilization of certain diagnoses codes varies widely on certain conditions, which increases inconsistency of data.⁹³ These CMS algorithm workarounds, while helpful to an extent, insufficiently capture such a diverse population. Further, they demonstrate the ways the health system, by design, renders transgender populations invisible and centers (albeit unintentional or not) a white supremacist and cisnormative fixation on the medicalization of transgender populations that are deeply rooted in historical violence and policing of gender non-conforming bodies.⁹⁴ For example, genital-reconstructive surgery, among other services, generally requires patients undergo two years of gender-affirmation hormone replacement therapy before they can qualify for coverage despite a gender dysphoria diagnosis. However, many transgender and non-binary individuals do not, or cannot, undergo GAHT. Some insurance plans require GAHT for chest reconstructive surgery, which has been widely performed on individuals not on GAHT.⁹⁵ “Transition-related” or “gender-affirming” treatment is different for every person and negotiated by many factors including health status, gender expression, source of insurance coverage, interactions with the carceral system, access to inclusive spaces, whether their state has trans-inclusive policies and protections, and several more.⁹⁶ Gendered policies only reinforce cisnormative systems that disproportionately deny care to non-binary individuals, persons with disabilities or chronic health conditions, and often transfeminine people of color.

While some states have passed laws requiring SOGI data collection, including within state Medicaid agencies, more must be addressed.⁹⁷ While SOGI data collection algorithms can

⁹³ *Id.*

⁹⁴ Charlotte J. Patterson et al., *Understanding the Well-Being of LGBTQI+ Populations* (2020), <https://www.nap.edu/catalog/25877/understanding-the-well-being-of-lgbtqi-populations>.; See also World Professional Association for Transgender Health, Inc., *WPATH clarification on medical necessity of treatment, sex reassignment, and insurance coverage in the U.S.A.* (Dec. 21, 2016), <https://www.wpath.org/newsroom/medical-necessity-statement>. “It is important to understand that every patient will not have a medical need for identical procedures. Clinically appropriate treatments must be determined on an individualized and contextual basis, in consultation with the patient’s medical providers.”

⁹⁵ See, e.g., *Flack v. Wisconsin Department of Health Services*, 395 F.Supp.3d 1001 (W.D. Wis. 2019)(finding that Wisconsin Medicaid’s longstanding coverage exclusion on gender confirming treatments and related services violated federal law); see also Nat’l Health L. Program, *Transgender Medicaid Beneficiaries Secure Victory in Landmark Class Action Health Care Rights Lawsuit Against State of Wisconsin* (Dec. 10, 2019), <https://healthlaw.org/news/transgender-medicare-beneficiaries-secure-victory-in-landmark-class-action-health-care-rights-lawsuit-against-state-of-wisconsin/>

⁹⁶ *Id.*

⁹⁷ See Taylor M. Cruz, *supra*, note 83; see also Cal. Gov’t Code § 8310.8; Cal. Educ. Code § 51514.



certainly reveal important information about LGBTQ health issues, they cannot fix them.⁹⁸ Beyond mere collection, there lies the logistics of how to use it and how to put it into action to tackle the unique health issues of LGBTQ populations and assist communities of color who experience compounded disparities. Only limited meaning can be derived without additional factors such as race and ethnicity, age, housing status, source of health coverage, and linking to patient behaviors recorded in EHRs to identify more rich information.⁹⁹

Poorly developed algorithms often perpetuate biases and misinformation about LGBTQ health.¹⁰⁰ Specifically, transgender and non-binary individuals are more likely to be uninsured, have low-income, and be non-Hispanic Black, and therefore need access to public health care such as Medicare or Medicaid.¹⁰¹ Such populations experience high rates of barriers to care if their state does not have Medicaid expansion or does not cover gender-affirming care.¹⁰² While LGBTQ health has certainly improved as a result of relatively recent advancements in the medical field and through data collection, health disparities persist.¹⁰³ Developing better algorithms is crucial to aid in meaningfully addressing disparities within this diverse population.

D. Maternal Mortality

There are vast racial disparities in maternal mortality and morbidity in the United States, with black women nationally three to four times more likely to die from pregnancy-related causes than white women.¹⁰⁴ Clinical tools, including algorithms, may exacerbate these disparities if not properly scrutinized. One such tool is the Vaginal Birth After Cesarean (VBAC) calculator, which estimates success rates for vaginal birth among pregnant people with a previous cesarean delivery.

⁹⁸ See Taylor M. Cruz, *supra*, note 83. For providers serving low-income communities, the intake process, which already solicits a lot of personal information, can overwhelm an already short and finite appointment window. Often, education about why SOGI data is so important, is also severely lacking. Additional factors, such as the cultural responsiveness or ability to properly translate SOGI questions can unintentionally alienate patients who come from different backgrounds.

⁹⁹ *Id.*

¹⁰⁰ See Foad Hamidi, *supra*, note 85.

¹⁰¹ See Wyatt Koma, *supra*, note 79.

¹⁰² *Id.*; see also Christy Mallory et al., *Medicaid Coverage for Gender-Affirming Care* (Oct. 2019), <https://williamsinstitute.law.ucla.edu/wp-content/uploads/Medicaid-Gender-Care-Oct-2019.pdf>.

¹⁰³ See Matthew B. Shabath, *supra*, note 85; see also S.E. James, *supra*, note 78.

¹⁰⁴ Ctrs. For Disease Control & Prevention, Reproductive Health, Pregnancy Mortality Surveillance System, https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Freproductivehealth%2Fmaternalinfanthealth%2Fpregnancy-mortality-surveillance-system.htm.



For pregnant people with a prior cesarean delivery, there are some safety concerns with a subsequent vaginal delivery, especially for people with more than two prior cesarean deliveries, prior classical incisions, or prior uterine surgery in which the myometrium was compromised.¹⁰⁵ However, there are also well-established health benefits for a successful VBAC compared to a repeat cesarean delivery, including avoidance of surgery and surgical complications, lower risk of postpartum hemorrhage and infection, faster recovery time, and lower risk of complications during subsequent pregnancies.¹⁰⁶ As result, clinicians use tools like the VBAC calculator, endorsed by the National Institute of Child Health and Human Development, to help providers individualize risk assessment for VBAC by accounting for specific risk factors discernible during a prenatal visit.¹⁰⁷

The VBAC calculator has two race-based correction factors that “subtract” from the overall likelihood of successful VBAC, meaning pregnant people identified as African American or Hispanic are systematically assigned a lower chance of successful VBAC than white women.¹⁰⁸ African American and Hispanic women already have higher rates of cesarean deliveries nationwide than white women.¹⁰⁹ So while decreasing the number of unnecessary cesarean sections is important to reducing racial inequities in maternal health outcomes, this is in direct conflict with the VBAC calculator algorithm. We know that providers are influenced by concerns over liability and perceived risk when counseling patients about a trial of labor after cesarean section.¹¹⁰ Because the algorithm dissuades clinicians from offering trial of labor to pregnant people with low VBAC scores, the race-based correction likely exacerbates racial disparities.

¹⁰⁵ Darshali A. Vyas et al., *Challenging the Use of Race in the Vaginal Birth After Cesarean Section Calculator*, 29-3 WOMEN’S HEALTH ISSUES 201 (2019), [https://www.whijournal.com/article/S1049-3867\(19\)30098-2/pdf](https://www.whijournal.com/article/S1049-3867(19)30098-2/pdf).

¹⁰⁶ Curtin, S., Gregory, K., Korst, L., & Uddin, S. (2015). Maternal morbidity for vaginal and cesarean deliveries, according to previous cesarean history: New data from the birth certificate, 2013. *National Vital Statistics Reports*, 64(4), 1–13.

¹⁰⁷ *Supra* Darshali A. Vyas, note 105.

¹⁰⁸ *Id.*

¹⁰⁹ Martin, J., Hamilton, B., Osterman, M., Driscoll, A., & Drake, P. (2018). Births: Final data for 2017. *National Vital Statistics Reports*, 67(8), 34.

¹¹⁰ Cox, K. J. (2011). Providers’ perspectives on the vaginal birth after cesarean guidelines in Florida, United States: A qualitative study. *BMC Pregnancy and Childbirth*, 11(1), 72.



Inclusion of race as a correct factor is based on observational data that showed, “Women who achieved successful VBAC were more likely to be Caucasian, married, privately insured, tobacco users, and to have BMI less than 30” when compared with those who were unsuccessful.¹¹¹ Yet among these descriptors, only race was incorporated into the final predictive model, the only variable without a clear biological connection to labor mechanisms.¹¹² At best, race is being used as a proxy for other variables that reflect the effect of racism on health care, like income, education level, and access to care.¹¹³ At worst, race is being used based on assumptions of pelvic difference in Black and Hispanic women that have been historically rooted in racist practices intended to create a narrative of women of color’s inferior reproductive ability.¹¹⁴

Using incidence data to justify race-based correction in the calculator is unfounded. Since the observational data reflect a snapshot in time, it is unsurprising that they reveal racial and ethnic disparities, which are prevalent in maternal health. However, incorporation of race-based correction in the calculator systematizes these existing disparities into a predictive algorithm ensures that these trends will continue, and thus perpetuates institutional racism. The algorithm can be used without race-based correction, as has been done in Canadian and Swedish research, or it can be adjusted to include additional upstream factors, such as parent’s level of education.¹¹⁵

While it is critical to acknowledge racial and ethnic inequities in maternal health outcomes, the inclusion of race as a factor in predictive algorithms has the potential to worsen existing disparities. The VBAC calculator must be updated accordingly. The VBAC calculator is just one example of racism in maternal mortality clinical decision-making and other tools need to be closely examined.

¹¹¹ Landon, M. B., Leindecker, S., Spong, C. Y., Hauth, J. C., Bloom, S., Varner, M. W., Gabbe, S. G. (2005). The MFMU Cesarean Registry: Factors affecting the success of trial of labor after previous cesarean delivery. 193(3) AM. J. OBSTETRICS & GYNECOLOGY 1016–1023.

¹¹² *Supra* Darshali A. Vyas, note 105.

¹¹³ *Id.*

¹¹⁴ *Id.*

¹¹⁵ *Id.*

III. Center the Person in Solutions to Bias in ADS

Unique individuals face the consequences of most health care ADS—the systems are making health care decisions on a range of issues including diagnosis, eligibility, care recommendations, service authorization, or service denial. Individuals are also supplying the data used as the basis for and to train health care ADS. Individuals are at the beginning and the end of these systems and are the ones impacted by any bias in the systems themselves or the processes around them, including any other human elements. Policy approaches to addressing bias in ADS needs to center around the harm any such bias does, which means it must center around the individuals impacted.

From early in the process with data collection, ADS processes need to be clear about why data is being collected, what data is optional to share and what is required, and what will be done with both optional and required data. To the extent that the data collected by the system is protected by health information privacy protections or not, this should be clear. Importantly, this disclosure needs to be in plain language that is easy to understand and clearly identifies the relevant data. Many people are used to releasing sensitive personal information to receive services, but this does not mean they should have to do so.¹¹⁶ Although a more diverse array of data may need to be collected to protect against bias and better inform systems, people should not be forced to disclose more data than necessary and should knowingly consent to disclosure or use of data.

Throughout the life cycle of ADS there must also be opportunity for meaningful public involvement. This means that sufficient information needs to be provided at all relevant stages so that interested parties can review and provide comment. While this is especially true for any ADS used by a government actor, an ADS generally should not be created and implemented completely in the dark without review. Too often ADS is not known about until it has already been implemented and people begin to be effected by it. Not only should the ADS life cycle be far more transparent, so should too any known limitations or bias of a given system. For example, if an ADS is intended, designed, and tested for a certain purpose and population, that should be clearly identified so that if it is used for someone outside that purpose and population they will know that the ADS may not be completely reliable. This is also important for any health care practitioner using ADS to help them make clinical decisions. Many health

¹¹⁶ See Danielle Keats Citron, *A Poor Mother's Right to Privacy: A Review*, 98 BOSTON UNIV. L. REV. 1139 (2018), <https://www.bu.edu/bulawreview/files/2018/10/CITRON.pdf>.



care ADS are making clinical decisions and should be treated more like medical devices for purposes of review and approval than some individual health care entity policy. People impacted by an ADS need to know that a specific ADS is being used on them, what it is doing, and the limitations of any outcome of the system.

Of particular importance is how and individual is informed of the outcome of an ADS. In NHeLP's experience, too often an ADS merely tells the final outcome and cannot meaningfully indicate *why* a particular decision was made. For example, as illustrated in the Arkansas HCBS case, the system could tell a person what level of services they were allocated but not what characteristics of their individual situation led to that result.¹¹⁷ For one individual, it may be that their pressure sore had improved from their previous assessment and thus the ADS resulted in the person being assigned to a lower resource utilization group and thus was allotted fewer service hours. But for the individual, they may feel that their health situation had deteriorated in other ways and they needed more services, so would likely not understand why their services were reduced.

This inability to understand why services changed as a result of an ADS is a common refrain and is reflected across the different areas in which NHeLP is aware of ADS being used, including eligibility and service denials.¹¹⁸ Although advocates have consistently enforced due process protections that require information to be provided about the basis of a decision about Medicaid services, they have often encountered problems with an ADS's limitations—the systems often cannot provide an audit trail or similar function to explain what in the information provided about the individual was relevant and why the ADS made the decision. In addition, many systems have significant problems with their notice function generally or have such static notices that any changes are difficult to incorporate into the system's notices.¹¹⁹ In one example, the State tasked an individual with interpreting the results of and HCBS assessment

¹¹⁷ *Ledgerwood v. Gillespie*, No. 3:16-CV-119, 2016 WL 11524464 (E.D. Ark. June 14, 2016).

¹¹⁸ For examples of NHeLP's experience with notice and ascertainable standards related to ADS, see, e.g., *Benjamin H. v. Ohl*, No. Civ.A 3:99-0338, 1999 WL 34783552 (S.D.W.V. July 15, 1999) (claiming the system used to evaluate individuals for HCBS was not ascertainable); *L.S. v. Delia*, No. 5:11-CV-354, 2012 WL 12911052 (E.D.N.C. Mar. 29, 2012) (challenging notices regarding the use of the SIS to establish budgets for services).

¹¹⁹ See, e.g., State of Colorado-Office of the State Auditor, Medicaid Client Correspondence Performance Audit (Sept. 2020), https://leg.colorado.gov/sites/default/files/documents/audits/1936p_medicaid_client_correspondence_-_september_2020.pdf (finding a high prevalence of notice issues from the Colorado Medicaid eligibility system).



and ADS to identify the minimum information to be provided to the affected individual. But advocates reported that this information was often still confusing. Advocates also report that even when pressed in a fair hearing, state officials often cannot meaningfully explain an ADS result.

While an ADS may involve complex analysis and programming, the end result must be something that is understandable by the individuals affected and it must provide not only the end result, but the relevant information and rationale used to get to that result. Without that information, not only will individuals be harmed by their confusion, but they will not be fully able to identify and fight when an outcome is wrong; including when the outcome is biased.

The impact of not having the information necessary to challenge the decision of an ADS can be incredibly significant. A denial of health care services can lead to poorer health outcomes, including death. In the HCBS context, people without services may have their health deteriorate, fall, lose employment, become more segregated from the community, or even become institutionalized. With fewer service hours, people who use HCBS may also not eat, bathe, or otherwise do tasks of daily living for extended periods of time as they wait for their aide to come for the limited hours they have been allotted. For ADS that determines eligibility individuals may be forced to stop medically necessary treatment when their coverage ends. The impact of a loss of health coverage is well-documented.

IV. ADS Will Be Imperfect and Biased. The Safety Net for its Decisions Must Not Be.

It is unreasonable to expect a given ADS to make the right decision for all individuals all the time. These are systems usually based on limited statistical modelling, imperfect data, and written rules geared toward “typical” situations that may overlook exceptional circumstances. Errors in ADS coding or data analysis are all too common, and bias infiltrates both system design and implementation. Policies about health care ADS should start from the assumption that some people will not fit within the ADS’s model. Operating from that assumption, policies can focus on the protective processes that should exist around any health care ADS.¹²⁰

¹²⁰ While many decisions made by ADS have due process protections, not all do. See generally Perkins, *supra* 21 (discussing when due process protections apply).



In addition to the meaningful, informative notices discussed above, there must be an easily accessible exceptions process that has clear guidelines. Such a process would include clear timelines, the ability to examine the decision and rationale behind the decision, an opportunity to show a service is necessary outside of the ADS's guidelines, and a timeline for a decision. A person must have an opportunity to show they are an exception to the ADS and meet well-accepted criteria for a service or procedure. Incorrect decisions or bias in health care ADS may not be completely preventable, but harm from those errors or bias is preventable, or at least redressable in a timely manner. Perfecting ADS may not be possible, but protecting people is. We would welcome opportunities to discuss further our comments or our work on health care ADS. If you have any questions please contact Elizabeth Edwards (edwards@healthlaw.org).

Sincerely,

A handwritten signature in black ink, appearing to read "Edwards", enclosed within a hand-drawn oval.

Elizabeth Edwards
Senior Attorney

David Machledt
Senior Policy Analyst

Skyler Rosellini
Senior Attorney

Liz McCaman
Staff Attorney

