



Principles for Fairer, More Responsive Automated Decision-Making Systems

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Summary of Principles

Many government agencies use automated decision-making systems (ADS) for public benefits coverage and enrollment decisions. By ADS we mean, broadly, systems that use standardized logic or algorithms to assess eligibility for and access to public benefits.¹ This includes not only sophisticated “big data” systems, such as programs that use machine learning to flag potentially fraudulent applications, but also much simpler protocols that enable coverage decisions with little or no active human judgment, such as evaluating eligibility criteria using available data.

At their best, ADS can facilitate access to needed services. For example, during the rollout of adult Medicaid expansion, many states used available data to identify adults enrolled in SNAP, the federal nutrition program for low-income people, and then sent these individuals shorter, simplified Medicaid enrollment forms.² This technological solution raised participation in the new Medicaid group by hundreds of thousands of people and opened the door to new opportunities for Medicaid and SNAP coordination.³

Unfortunately, ADS can also complicate access to public benefits or challenges to adverse decisions. Some ADS act like a “black box” by masking the underlying criteria that inform their outcomes – including discriminatory outcomes. Claims to proprietary information or concerns about “gaming” the system may thwart efforts to learn how different ADS work. Poor design, faulty or missing data, and other implementation issues can cause automated systems to fail outright or fail to anticipate unexpected circumstances. Resulting service and coverage losses may affect whole populations, and often fall disproportionately on marginalized groups. One screening tool for Medicaid home and community-based services (HCBS) systematically failed to find people with cerebral palsy eligible because coding instructions did not match the eligibility criteria.⁴ In other cases, biased underlying data has led to outcomes that reproduce or even exacerbate historical inequities, such as systems that deny care to Black patients based on historic use data rather than need.⁵

People on Medicaid and other federal entitlement programs have legal protections that, when enforced, can address some of these problems. For example, NHeLP has successfully relied on constitutional due process protections to require states to use “ascertainable standards,” or put simply, to explain the criteria for decisions rather than simply stating the result.⁶ We have also challenged the transparency of criteria to determine services and how assessment tools are used in that process.⁷ While these tools cannot fully prevent the design and use of bad ADS, they have mitigated harms in a number of states.

Our long history of advocacy has encouraged us to think about preventive advocacy rather than only addressing ADS after they have begun to harm individuals.⁸ The broad principles described below outline how to realize the benefits of ADS while minimizing drawbacks. From ensuring meaningful beneficiary input during design to incorporating transparency, effective due process protections, privacy protections, beneficiary outreach, and system oversight after implementation, the principles cover the complexities of building successful ADS.

Each principle is described briefly below. Click on the principle for a more detailed description.

[Principle 1. Transparency](#) – Those creating ADS must promote transparency across the ADS life cycle phases: devising, contracting, building, operating, and revising.⁹

To build trust in any automated system, states and other entities must create a meaningful stakeholder process, including strong public notice and comment, and public accountability through each developmental phase. Without this input, issues with the system will likely only appear after people lose essential benefits. Tactics to improve transparency could include a commitment to testing for flaws and piloting new ADS with beneficiaries and beneficiary advocacy groups before implementation. Governments can also establish a standing stakeholder advisory committee that prioritizes the participant perspective and provides input before contracting begins.¹⁰ A state’s ongoing commitment to testing and evidence-sharing on ADS outcomes during implementation improves transparency and helps identify problems early.

[Principle 2. Protect Civil Rights](#) – The use of ADS in entitlement benefits programs, such as Medicaid, must adhere to all civil rights and due process requirements.

Constitutional due process has been interpreted by courts to include a right to have “ascertainable standards” govern entitlement benefits programs. In short, people seeking benefits have a right to know the reasons behind decisions made about their eligibility and benefits so that they can decide whether and how to appeal those decisions. However, ADS often fail to adequately describe the reasons for the outcomes they produce, making it more

difficult for a person to understand and appeal. Claims to proprietary intellectual property by some ADS contractors and Managed Care plans often conflict with due process requirements and further undermine transparency. States implementing ADS in entitlement benefits programs must meet all constitutional due process requirements, including notice, ascertainable standards, and access to fair hearings. ADS for these programs must also adhere to all applicable civil rights protections.¹¹

Principle 3. User-Focused – Agencies and vendors designing ADS must center end users’ experiences at all phases of the ADS’ life cycle.

ADS often incorporate population-level data that reduce the complexities and contradictions of individual lives into averages. A successful beneficiary-focused ADS acknowledges these often challenging individual living circumstances by building in mechanisms to accommodate individual complexities, prioritizes timely access to benefits, and minimizes administrative burdens that delay care. A beneficiary-centered ADS integrates users’ perspectives in all phases of design, development, implementation, and revision. The design and testing process should seek (and financially support) active participation from the full range of people who use the program and their advocates. After implementation, clear, easy beneficiary feedback loops help identify problems and inform revisions.

“User experience” includes beneficiaries’ experience interacting with the ADS. A successful ADS is accessible – including plain language interfaces and explanations, appropriate translation and interpreting services, as well as appropriate formats for people with disabilities. It also promotes usability, such as forms pre-filled with available user data, strong standards to protect data privacy, and clear notices to inform beneficiaries how to appeal.¹²

Principle 4. Validity – Agencies must ensure that each ADS accurately and consistently measures what they claim it measures, according to its clearly articulated purpose.

ADS developers should articulate a clear purpose for the ADS at an early stage. Part of the development process must include an analysis to identify potentially confounding factors in the data that may influence outcomes. For example, an ADS that purports to measure someone’s functional needs should not produce outcomes affected by geographic wage differences or setting choice.¹³ If it is not possible to avoid confounding factors, the articulated purpose should explicitly acknowledge major factors and explain how the ADS will mitigate its effects. Finally, the ADS results and purpose must conform with applicable state and federal laws, regulations, and policies.

Principle 5. Mitigate Bias – Agencies should carefully and regularly review and, as needed, revise their ADS to minimize outcomes that exhibit bias against protected communities and prevent ADS access barriers to needed benefits.

Many ADS used for administering public benefits draw on fundamentally-flawed data that produces biased outcomes.¹⁴ The burden of proof should be on ADS developers and states to show affirmatively that their ADS reduces, or at least does not worsen, disparate impacts on protected classes. While most evidence of disparate impact focuses on race/ethnicity/language, evaluations should also consider disability, socioeconomic status, sexual orientation and gender-identity, age, economic status, and other potentially discriminatory factors.¹⁵ States should look beyond just the data used as input and the automated decision-making logic. They should develop trainings for agency employees and relevant contractors who administer the ADS on strategies to recognize and reduce potential implicit and explicit bias, mitigate potential conflicts of interest, and ensure the ADS supports participants' legal rights.

Principle 6. Humility & Redundancy – In full awareness of ADS' practical and fundamental limitations, agencies and vendors should incorporate human oversight and feedback loops to identify and correct expected errors at the individual and, if needed, systemic level.

Creating a beneficiary-centered ADS requires the humility to understand technology's limits and the awareness of the potentially life-changing and long-lasting consequences of improperly denied or delayed benefits. Systems should include well-publicized human oversight and feedback loops such as manual override capabilities and protocols for accessing exceptions processes that can correct mistakes and outliers. ADS oversight tools and reporting requirements should track and flag systemic flaws that can inform progressive ADS revisions.

Conclusion

A more thoughtful, beneficiary-centered approach to identifying and minimizing ADS' harm is long overdue, especially as use of ADS surges and ADS fairness theories continue to leave out the perspectives and rights of Medicaid and other public program beneficiaries.¹⁶ While we have focused on public benefits programs, many of these principles have broader applications. With careful attention to the above principles, ADS could help reduce inequities in access to public benefits, improve participation, reduce churn, and ultimately improve outcomes for affected individuals. But implementing ADS without careful planning and attention to beneficiary-focused principles reproduces existing biases, increases barriers to services people are eligible to receive, and leads to unfair and inequitable outcomes that serve no one.

Discussion

Principle 1. Transparency – Those creating ADS must promote transparency across the ADS life cycle phases: devising, contracting, building, operating, and revising.

To build trust in their ADS, states should create an open process through each phase of the ADS cycle. This commitment to transparency requires repeated stakeholder engagement, public accountability and oversight, and active testing. Perhaps more than anything, states must clearly understand that while algorithms may hold promise to streamline bureaucracy, they also have practical and fundamental limitations.

Clarify the purpose publicly

While designing any ADS, states or other developers should clearly articulate the purpose, justification, and scope for each algorithm used in its public benefit programs. The statement of purpose should align with the program's purpose and objectives and with existing policy and law.

Seek active, broad, and repeated stakeholder engagement

A transparent ADS process commits to recurrent engagement with stakeholders, especially stakeholders who use the program. This engagement must include ample opportunities for public notice and comment on both new ADS and periodic efficacy reviews of existing ADS. Unfortunately, meaningful opportunities for public comment on ADS remain quite rare.¹⁷ Public comment opportunities should encompass at least:

- The state's proposal to develop, use, and periodically review an ADS;
- its description of the purpose, target population, potential risks or negative impacts, and evidence supporting the data quality, validity, and reliability, including a plain language version of this information;
- ADS-related requests for proposals; and
- Reports related to the equity impact of an ADS.

States should regularly post Requests for Proposals and any awarded contracts as well as performance reports so the public knows who is vying for these contracts and can investigate their track record in other states to inform public comments. Already implemented ADS should have systems to monitor outcomes, periodically assess their effectiveness, and consider needed changes. Any substantial changes to the ADS should automatically trigger stakeholder engagement, including a public notice and comment process.

While public notice and comment is necessary, effective stakeholder input must go further. States could also convene a standing stakeholder advisory group with potentially affected beneficiary representatives who can help state officials judge what access barriers the ADS might cause for people seeking benefits. An advisory group allows members to share their perspective as end users while gaining expertise in the bureaucracy and technical side of ADS. A successful body must include compensation for beneficiaries' time and insight.¹⁸ For example, California holds quarterly user testing with consumer advocates to test updates to the state's online single, streamlined application system. The ongoing meetings have helped ensure compliance with state and federal laws, as well as the usability of the functions for consumers. Of course, advisory groups with only token beneficiary representation, that lack real influence, or that require in-depth expertise without support or access to necessary information, often likely do more harm than good.

Additionally, vetting new or revamped ADS with end users can help identify weaknesses. When Missouri officials allowed legal aid advocates to preview a proposed assessment tool, the advocates quickly identified numerous coding flaws that would render thousands of users ineligible.¹⁹ Similarly, sharing sample notices including the ADS populated fields and options with a beneficiary stakeholder group can highlight confusing or unclear explanations as well as accessibility concerns. As with advisory groups, beneficiaries and legal advocates should not bear all the burden of finding problems in a proposed ADS and should receive adequate compensation for their work. States should build stakeholder testing into the ADS budget alongside other routine testing for statistical validity (accuracy), reliability (consistency), and potential disproportionate impact.

States must provide evidence of an ADS's efficacy and outcomes

Finally, states should publicly share the evidence that supports an ADS' validity and reliability before implementation. In Medicaid, states often borrow tools from other states or purchase off-the-shelf private products that may not be appropriate for the target population.²⁰ The ADS development process should explicitly address whether a borrowed or bought product can validly apply in a different place or program. Any identified issues must be addressed and tested *before* deploying it.

Transparent ADS design and implementation would make available all supporting and critical studies during development, alongside explanatory justifications for moving forward. Testing a new ADS against existing standards to evaluate potential implementation impacts should be standard practice. And finally, the design must include reporting mechanisms for future validity and reliability tests of the ADS after implementation. This includes regular reliability tests for

human operators of ADS as well as using utilization and eligibility data to track positive and negative outcomes over time. Ongoing stratified reporting can help train algorithms and ensure they are not disproportionately affecting beneficiaries.

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Principle 2. Protect Civil Rights – The use of ADS in entitlement benefits programs, such as Medicaid, must adhere to all civil rights and due process requirements.

Too often, people seeking access to public benefits are denied without knowing why. Medicaid advocates have used constitutional due process arguments to force greater transparency and protections for such individuals. Appropriate notice and clear communication of the reasons for a decision are fundamental to proper administration of an ADS throughout the benefits process. Too often, notices include indecipherable references to scored results or ADS outcomes that fail to clearly explain why an individual has been found ineligible for a Medicaid program or services.

For example, a person denied care may simply be told the results of the ADS without any information about what factor(s) actually triggered the denial, which may discourage them from appealing the denial. For example, if a notice simply states an applicant's income was too high without specifying the calculated income, the applicant would not be able to tell whether the determination was based on accurate data. Even if a person learns about how a decision was made, they may have no viable avenue to challenge the assumptions or bases of the decision making tool if those assumptions are secret. In some cases, MCOs have shielded detailed explanations from enrollees by claiming the results are proprietary information. Such arguments should be given little weight given the compelling interest beneficiaries have to receive needed benefits in a timely way.²¹ Simply put, notices must include plain-language explanations of how an ADS system arrived at a decision or outcome, and what is the data that led to that decision.

States must consider and build in such transparency and oversight into contracts with ADS developers. Even if a state agrees to clarify notice explanations, technological limitations of an ADS can get in the way. Some ADS were not designed to facilitate audits or troubleshooting. Even simple reports may be impossible, let alone more systemic evaluations like disparate impact analysis. Putting in place needed changes after ADS implementation can be expensive, especially compared to costs of building such features into the system from the beginning.

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Principle 3. User-Focused – Agencies and vendors designing ADS must center end users’ experiences at all phases of the ADS life cycle.

From design and procurement through implementation and ongoing monitoring, ADS must center and be responsive to the individuals who will ultimately use the benefits. These systems can profoundly shape people’s lives and futures, and their design should reflect that reality. Policy approaches need to anticipate how ADS can harm timely access to services and introduce bias, and minimize those delays or failures. Design should not center on the “typical” user, but rather on the breadth of lived experiences of all its users and how they typically interact with the benefits program. A successful ADS will also attend to each individual with their own characteristics and health needs and accommodate unusual circumstances by allowing for overrides, exceptions, and similar interventions.

For example, the Affordable Care Act included policies intended to simplify user experience with the system while expanding the pathways to accessing services.²² It established eligibility standards that advanced no-wrong door access to health coverage benefits. It reformed the application and redetermination process such that, where possible, states must automatically renew eligibility if possible and if not, must pre-fill forms with already available beneficiary information. The ACA approached eligibility and enrollment in relevant programs with a focus on processes “structured to maximize an applicant’s ability to complete the form satisfactorily, taking into account the characteristics of the individuals who qualify for [applicable programs].”²³ The ACA also removed some asset tests that created administrative hurdles to eligibility, prohibits questions not relevant to the eligibility determination on the application, and limits how often states can conduct redeterminations.

Despite the ACA’s efforts to strengthen usability standards, ADS for eligibility determinations often fail to meet, let alone exceed, that bar. Stakeholder testing and feedback during the design phase, as described above under Principle 1, could provide valuable information about how an ADS will affect users and can help identify problems before launch. Other tactics such as testing notices and communications for easy readability similarly emphasize the ADS’ user interface. Such policies can facilitate access to benefits for those who qualify, and set the stage for a beneficiary-centered approach to automation. At the other end, building in redundancies and clear pathways to appeal, described in Principle 6, can ensure that outlier cases where an individual falls through cracks in an ADS’s logic do not lead to access barriers.

Systems must be accessible to the range of potential users

This “user-focused” principle encompasses the notion that ADS must be accessible across diverse user populations. System tests should demonstrate that they work not only on computers, but also on mobile devices, which many beneficiaries primarily use for internet access. All platforms, including electronic, paper, and telephonic, platforms must be accessible to people with disabilities and people with limited English proficiency. A whole range of practices fall under this principle, ranging from providing translated documents and oral interpreting services to readability tests. As described in [Principle 1](#), beneficiary involvement is often key to success in fulfilling this principle of accessible ADS design and deployment.

Language and communication access must be provided consistent with all relevant civil rights laws, including Title VI of the Civil Rights Act, Title II of the Americans with Disabilities Act, §§ 504 and 508 of the Rehabilitation Act, and § 1557 of the Affordable Care Act.²⁴ That means ADS for public benefits and any related communications, instructions, or information related must be accessible to beneficiaries with limited English proficiency and people with disabilities. For example, a translation of a functional assessment must be completed by culturally competent translators (and ideally field tested by users with limited English proficiency) to ensure that the questions have the same meaning and will elicit the same type of response. Machine translation (also called automated translation software) should be discouraged. If used, it must be reviewed for accuracy by qualified translators. Interpreters must be readily available for any individual who requires that support. Websites and other information and communication technologies should conform to current content accessibility standards, such as the Worldwide Web Consortium's Web Accessibility Initiative's Web Content Accessibility Guidelines (WCAG) and include information in relevant non-English languages to help people with disabilities and people with limited English proficiency understand how to request communication assistance.²⁵

In addition to robust usability testing and minimally required accessibility, people with disabilities and people with limited English proficiency need to have access to meaningful assistance and accommodations to navigate the system. A person with intellectual disabilities may struggle to understand the system even if it has passed a general accessibility test. In another example, a person may need assistance understanding written language or certain terminology depending on their background or disabilities.

If a system accepts documents from participants for input into the ADS, instructions must clearly detail accepted formats and instructions. Those formats should include options commonly available to those who rely on mobile devices. For example, a picture of a document could suffice to verify income or address, particularly for providing supporting evidence such as a bank statement or utility bill. Too often, systems winnow people out by

sheer frustration with onerous documentation requirements, lack of customer support, or overly restrictive compatibility requirements.²⁶ An ADS that abides by this beneficiary-centered principle would look for mechanisms to maintain program integrity that do not subvert access to benefits.

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Principle 4. Validity – Agencies must ensure that each ADS accurately and consistently measures what they claim it should measure, according to its clearly articulated purpose.

In practice, ADS often do not do what contractors say they do. State systems are often adapted – or simply borrowed – from research or commercial products that had a different original purpose, asked slightly different questions, or drew on data from a different context. Any entity seeking to use ADS for benefit administration should detail the purpose and scope of the proposed ADS. Designers should define and carefully review the data sources that inform their algorithms to account for any confounding factors, known deficiencies, or inequities.²⁷ The standards set forth in the original design documents, contracts, and business rules should reflect the intended purpose, function, standards, quality control mechanisms, and other necessary aspects of the ADS.

Consider Medicaid HCBS functional assessment tools, which generally purport to measure an individual’s cognitive, social, and physical abilities. The Supports Intensity Scale (SIS), one widespread Medicaid HCBS assessment tool, claims to “assess and describe the pattern and intensity of supports an individual needs to have in order to meet the demands of their environment.”²⁸ In some states, SIS informs individual’s service budgets. But translating functional acuity into service allocation is a complicated process that incorporates much more than just an individual’s functional needs. Resource allocation models may implicitly or explicitly factor in geographic variation in wages, varying settings costs for similar care, or the availability of unpaid informal caregivers. If a resource allocation ADS does not appropriately account for these variables, it may produce results that, for example, improperly compel family to provide unpaid supports, and unfairly penalize individuals who have no family to help them or who live in a more expensive region in the state.²⁹ More broadly, budget models based on historic utilization data may simply reproduce the underfunded HCBS programs of the past. North Carolina advocates have brought multiple cases involving the use of the SIS, fighting the reliance on the assessment along with the accompanying budgeting tools, including whether they were used to impose across-the-board service reductions that failed to consider certain important factors.³⁰ Mismeasurement is one of the most common ways that ADS introduce and simultaneously mask bias and discrimination.

Some measurement errors in eligibility systems are simply the product of poor coding or logistical oversights. In Arkansas, simple coding errors led to the accidental miscategorization of individuals with cerebral palsy and diabetes into lower need groups, leading to service cuts.³¹ Such errors can seriously affect individuals, but can be impossible to detect if the underlying data and model are unavailable. An open, intentional design process can help minimize such risks.

In some cases, an algorithm may produce results that misalign with state or federal laws and regulations on eligibility or due process, thus leading to erroneous outcomes. For example, when Wisconsin automated a system to determine whether Medicaid HCBS waiver enrollees met the regulatory definition of having an intellectual or developmental disability (IDD), hundreds of people received termination notices. Advocates quickly identified that the new screening tool was misclassifying people with cerebral palsy and similar conditions as not meeting the federal definition.³²

Finally, some ADS outcomes may be the result of bad faith design and may be implemented as part of a larger set of policy changes designed to cut back on benefits. Created under the banner of increased efficiency and objectivity, the underlying rationale behind the implementation of an ADS may instead prioritize cost-savings at the expense of beneficiaries' needs. Utilization management tools may weigh financial factors over widely accepted clinical criteria.³³ The use of ADS may reflect successful efforts by sales-people or lobbyists' claims about its purported benefits. Systems originally built to target fraud may end up being used as data sources for eligibility or service-authorization decisions.³⁴ Adapting an ADS to a purpose for which it was not designed or tested can result in harm to beneficiaries.

Therefore, government officials need to articulate both the need for an ADS and its underlying purpose, as described in [Principle 1](#). Was it developed to cut costs? Was it developed by a rural health clinic and is now being applied much more broadly? Or was it developed in response to research that identified certain correlations among a study population and expanded to an ADS for clinical purposes? What assumptions were included in the identified need and purpose? Much like any scientific study, examining the original question or hypothesis itself can reveal potential sources of bias.

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Principle 5. Mitigate Bias – Agencies should carefully and regularly review and, as needed, revise their ADS to minimize outcomes that exhibit bias against protected communities and prevent ADS access barriers to needed benefits.

Health care has a long and checkered history of egregious biases resulting from practices that centered the white, male, heteronormative experience while pathologizing others.³⁵ Biases have been documented in everything from data collection to research methodologies, diagnostic tools, and accessing care.³⁶ Is it a coincidence that research journals with little staff diversity produce a dearth of studies explicitly assessing racism's direct effects on health?³⁷

Unsurprisingly, ADS (and the underlying data they use) too often also discriminate against people the health care system has historically marginalized. Cloaked by neutral sounding terms like standardization and automation, ADS may appear to reduce bias by masking the capriciousness of human decision-makers.³⁸ But humans design and implement every ADS, and their decisions shape every outcome.³⁹ For example, a machine algorithm intended to help radiologists find anomalies in chest x-rays systemically underdiagnosed young women, Black and Latinx patients, and people on Medicaid.⁴⁰ Researchers attributed the bias to a clinical history of underdiagnosis in the underlying data amplified by the training algorithm. Even if such systemic biases ADS reproduce go unnoticed, their disproportionate effects cannot be missed.⁴¹ In addition to the discretionary and potentially based decisions humans make in designing and building ADS, these systems often rely on standardization, which will always work for some and not others, and which will more often fail people in unusual circumstances.

Put onus on developers to prove their ADS does not discriminate

Due to the pervasiveness of bias in data systems, the whole life cycle of ADS development, procurement, and implementation must anticipate the potential for discriminatory outcomes. No one should assume that ADS are neutral. Rather, the developers should have to provide clear evidence their systems do not discriminate, such as through an ADS equity impact analysis; although current examples of these often have limitations.⁴² Such an analysis must be transparent and replicable based on available data and processes. Not only should developers publicly document the validity and reliability testing of any new ADS, but they should test the new ADS against existing protocols to measure potential disproportionate outcomes. If this requires a data collection system that can capture the target population's key demographic information, then a mechanism to collect and analyze that data must precede implementation of the new ADS.

Similarly, if an ADS relies on underlying data or methodologies with known discriminatory effects, such as the Quality-Adjusted Life Years (QALYs) metrics that are often used in

comparative effectiveness research but have been found to undervalue the quality of life of people with disabilities, such deficiencies should be eliminated before implementation.⁴³ The methodology of such corrections and related testing must also be transparent.

After implementation, ongoing active monitoring of the reliability, accuracy and equitable impacts of a new ADS should continue. Any errors, bias, or limitations identified should be publicly posted, discussed, and mitigated through revisions. ADS contracts must include provisions requiring immediate or ongoing system change orders (rather than waiting until the next contract period) for instances of systemic bias. Pending ADS revisions, any notices of benefits decisions using that ADS should include descriptions of its known problems.

Incorporate broad demographic data collection

We recognize the centrality of race, ethnicity, and preferred language in any analysis of bias in ADS, but developers should also examine additional demographic characteristics. Data collection, research, and analysis of public benefit systems shows pervasive evidence of discrimination across multiple identities including race and ethnicity; language; disability; age; sexual orientation, gender identity, and sex characteristics (SOGISC); as well as other factors.⁴⁴ Unfortunately, systematic collection of broader demographic data for entitlement benefits programs remains far from routine.

Often, the standards for data collection do not capture key information necessary to identify groups subject to bias. For example, many health care algorithms ask about sex and gender by way of a binary question: is a patient “male” or “female”?⁴⁵ Binary sex classifications inherently suppress information about some individuals by erasing the identities of transgender and non-binary individuals.⁴⁶ This also fails to capture information about people whose sex development or traits may not conform with “male” or “female,” including people who are intersex. Due to such shortcomings, transgender, non-binary, and intersex people remain largely invisible. It comes as no surprise that they also represent some of the most medically underserved populations in the U.S.⁴⁷ Without dedicated efforts to create and improve ADS to capture a broader, more inclusive, array of demographic characteristics, systems miss the opportunity to identify important disparities – including compound disparities experienced by people who belong to multiple marginalized groups.

Targeted interventions to build a more equitable and responsive health system for transgender and non-binary individuals depends on that basic demographic data collection, but only if adequate privacy protections and use restrictions are in place.⁴⁸ Such protections become even more important as some state and local governments enact transphobic policies and have even sought individualized data on gender changes.⁴⁹ In such a climate, responsible data

collection must clearly inform participants of its specific purposes, limit uses to those that specifically advance health equity for trans and non-binary people either individually or generally (as in the study of population health), prohibit uses that target or exclude individuals on the basis of demographic traits, and clearly explain the safeguards that prevent abuse to allow people to feel more comfortable sharing their demographic data.⁵⁰

For now, only a few federal and state agencies are collecting SOGISC data, and variable collection methods produce inconsistent data that can hinder accurate application processing, quality monitoring, and how health disparities are addressed.⁵¹ A recent National Academies of Sciences, Engineering, and Medicine report details how state Medicaid agencies or Medicaid managed care plans could best collect SOGISC data in a consistent form.⁵² Other federal committees have weighed in on the importance of protecting and de-identifying demographic data, including unique risks for some LGBTQI+ people.⁵³ The Federal Committee on Statistical Methodology has created a Data Protection Toolkit to provide some best practices, including creating data tiers that restrict access to more individualized data for only specific researchers and research purposes.⁵⁴ While a uniform requirement that public benefits programs collect and protect SOGISC data may remain a ways off, actively addressing these privacy concerns will be essential to build community trust and encourage people to self-report their demographic data. Realizing the potential benefits of making health disparities visible will depend on earning that trust.

Disability and reproductive health data collections also share similar concerns related to data protection and risks of re-identification that could lead to targeting.⁵⁵

Promote Independent, conflict-free assessment of individual needs

ADS design and implementation should minimize effects from financial incentives, including limiting conflicts-of-interest and avoiding incentives that reward limiting access to a benefit or program. Misguided financial incentives can range from provider self-enrichment to over-emphasis on fraud detection that depresses enrollment to managed care companies seeking profit by denying care indiscriminately. Financial incentives for system performance metrics may value processing speed over accuracy, leading to more frequent errors. System design may make such incentives or their impacts hard to see. A state may neglect or decline to build checks or audit trail capabilities such that financial malfeasance becomes difficult to track.

Unfortunately, existing federal conflict-of-interest protections do not anticipate all the possible incentive imbalances. For example, in Medicaid HCBS, functional assessment conflict-of-interest protections generally prevent providers from assessing individuals for whom they provide services – to protect against overuse of services. Other types of conflict-of-interest,

such as a managed care companies' potential financial benefit from denying or reducing authorized services, receive much less regulatory oversight.⁵⁶ Many managed care plans assess their own enrollees to determine care needs. It is hardly uncommon to find reports suggesting managed care plans have arbitrarily denied or cut back on services for enrollees with disabilities.⁵⁷ A participant-focused ADS committed to eliminating bias would broaden and strengthen conflict-of-interest protections to encompass these and other potential financial incentives that could affect ADS outcomes.

Train the operators to reduce discrimination

Few ADS are fully automated, and implicit and explicit bias have been documented in the workers who administer public benefit programs.⁵⁸ Part of ADS oversight must track performance of workers running the assessments, processing the applications, and authorizing new services. They must receive appropriate training and testing to maximize their accuracy, reliability, and ability to communicate with and appropriately answer beneficiaries' questions.

In some cases, the structure of teams using ADS can affect reliability. For example, one report of the SIS HCBS assessment in Virginia and Oregon found tremendous differences in who conducted the assessment. Virginia used over 500 case managers with minimal training to administer the assessment tool, while Oregon gave that responsibility to a small, highly trained team of officials who focused exclusively on assessments.⁵⁹ This difference generated far more consistent assessment results with the smaller team, even though both states used the same tool. Such consistency is necessary for an ADS, but it alone does not equate to ADS fairness or efficiency. Consistency from automation is often associated not with eliminating bias, but with trading the possibility of human bias with a guarantee of systemic bias.⁶⁰

The ADS design and procurement process should clearly delineate which employees will implement various aspects of the system and how their roles shape outcomes for the people seeking benefits. Any plan to administer an ADS should include regular training in how to administer the tool as well as how to recognize implicit bias. Workers must be able to answer common beneficiary questions, such as why the information is needed, how their data may be used, and what privacy protections are in place to protect their data. While providing beneficiaries with the information they need to make informed decisions is paramount, staff discomfort can also create a barrier to collecting demographic data.⁶¹ Confusion over requested information may otherwise impair data accuracy. Workers using ADS should be periodically evaluated not only for consistency but also for their familiarity with how to deal with unusual situations. Such atypical situations often cause individuals to fall through the bureaucratic cracks and end up not receiving benefits they should.

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Principle 6. Humility & Redundancy – In full awareness of ADS’ practical and fundamental limitations, agencies and vendors should incorporate human oversight and feedback loops to identify and correct expected errors at the individual and, if needed, systemic level.

We should never expect a given ADS to make the right decision for all individuals all the time. These systems depend on statistical modeling, imperfect data, and written rules geared toward “typical” situations that may overlook exceptional circumstances. Modeling and standardization by definition miss at least some cases—otherwise tools would simply enumerate the conditions of every single person. Errors in ADS coding or data analysis are all too common, and bias infiltrates both system design and implementation. ADS development should start from the assumption that some people’s complex living situations will not fit within the ADS’ model. Operating from that assumption, policies should focus on the legally required protective processes to ensure those individual “outliers” are identified, get accommodated quickly, and that their situations get incorporated into subsequent ADS review and revisions.

Part of designing the ADS must include a feedback system to identify, track, and later address problems or issues that arise in the field. For example, a system built on data from a different region or populations may not properly assess people’s experiences in the new region, population, or program.⁶² Creating an ombuds function with the dual responsibilities to help people understand and navigate the ADS and to collect and report on common problems it identifies could help address such issues. Another approach could involve periodically interviewing users (both enrollees and people who received denials) as well as ADS administrators to identify common problems and outliers, the quality of user experience, and potential biases. Whatever approaches developers may use, there should be a process in place *before and after implementation* to compile such feedback as part of periodic ADS review and revision.

What does it look like to create room for being human? It could be adding points in the system where a person can indicate “other” or “unsure” rather than answering a yes/no question that makes it impossible to complete the process. States should clearly specify who can make a change after an ADS error or oversight, and how beneficiaries can reach that person. Clear policies must delineate how much weight an ADS result carries and how it shapes service authorization. A binding assessment ADS result should raise red flags. If the ADS is considered a guideline, how do care managers discuss the system’s outputs or results with beneficiaries accessing services without unduly influencing the outcome?⁶³ The role for human intervention extends through a robust notice and appeals processes.

In addition to the meaningful, informative notices discussed in [Principle 3](#), there must be a clear, easily accessible, and well publicized exceptions process. Public benefit programs with due process protections, such as Medicaid, should require that exceptions process have all of those constitutional protections. Any exceptions process must include the ability to examine the decision and rationale behind the decision, and a person must have an opportunity to show that despite the outcomes produced by the ADS, they meet the criteria for a service or procedure. The exceptions process should define clear timelines, including a timeline for a decision with all accompanying due process rights.

Incorrect decisions or bias in 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.

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Endnotes

¹ An algorithm is any set of rules or step-by-step instructions to follow in performing a calculation.

² Jocelyn Guyer et al., Kaiser Comm'n on Medicaid & the Uninsured, *Fast Track to Coverage: Facilitating Enrollment of Eligible People into the Medicaid Expansion* (Nov. 2013), <https://www.kff.org/wp-content/uploads/2013/11/8517-fast-track-to-coverage-facilitating-enrollment-of-eligible-people-into-the-medicaid-expansion1.pdf>.

³ Jennifer Wagner & Alicia Huguélet, Ctr. on Budget & Policy Priorities, *Opportunities for States to Coordinate Medicaid and SNAP Renewals* (Feb. 2016), <https://www.cbpp.org/research/health/opportunities-for-states-to-coordinate-medicaid-and-snap-renewals>.

⁴ See, e.g., Benefits Tech Advocacy Hub, *Wisconsin Medicaid Home and Community Based Services Terminations*, <https://www.btah.org/case-study/wisconsin-medicaid-home-and-community-based-services-terminations.html> (last visited Sept. 15, 2022). In Wisconsin, advocates identified that the new screening tool for the IRIS program was terminating people with CP and other conditions from the program for not meeting the level of care necessary, even though they did. The system was programmed to exclude people who have only developmental disabilities (and not intellectual disabilities) even though they should also qualify for this waiver. *Id.*

⁵ 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>.

⁶ Jane Perkins, Nat'l Health L. 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 L. 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 L. 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, Nat'l Health L. Program, *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, Nat'l Health Law Program, *Preventing Harm from Automated Decision Making Systems in Medicaid* (June 14, 2021), <https://healthlaw.org/preventing-harm-from-automated-decision-making-systems-in-medicaid/> (discussing examples of harm and citing through hyperlinks and related resources other examples harmful ADS and sources of bias, including related cases).

⁸ *Id.*; Elizabeth Edwards et al., Nat'l Health Law Program, *Comments in Response to the AHRQ RFI on the Use of Clinical Algorithms that Have the Potential to Introduce Racial/Ethnic Bias into Healthcare Delivery* (May 4, 2021), <https://healthlaw.org/resource/nhelp-ahrq-comments/> as incorporated and added to in comments to NIST by Elizabeth Edwards, Nat'l Health Law Program, *Comments on NIST Proposal for Identifying & Managing Bias in AI* (Sept. 15, 2021), <https://healthlaw.org/resource/comments-on-nist-proposal-for-identifying-managing-bias-in-ai/>; Benefits Tech Advocacy Hub, www.btah.org; see also Mara Youdelman et al., Nat'l Health L. Program, *NHeLP Comments on Section 1557 Proposed Rule* (Oct. 3, 2022) (describing sources of discrimination and particularly discussing bias in clinical algorithms, benefit design, access to technology, and data).

⁹ For more on the ADS lifecycle, *see* Benefits Tech Advocacy Hub, www.btah.org (last visited Feb. 21, 2023).

¹⁰ *See, e.g.*, My Choice Matters: Community NOW, Idaho Dep't Health & Welfare, <https://healthandwelfare.idaho.gov/services-programs/community-now>. This group of adults with intellectual and developmental disabilities, family advocates, providers, and other stakeholders was formed in response to the *K.W. v. Armstrong* litigation regarding the use of ADS regarding the Supports Intensity Scale (SIS) and provides stakeholder input regarding the Medicaid Adult Developmental Disability (DD) program in Idaho, including the development of new tools for assessing needs and allocating services. *Id.*; *see also* Benefits Tech Advocacy Hub, *Idaho Medicaid Home and Community Based Services Care Cuts*, <https://www.btah.org/case-study/idaho-medicare-home-and-community-based-services-care-cuts.html>.

¹¹ *See, e.g.*, Title VI of the Civil Rights Act of 1964, 42 U.S.C. § 2000d et seq.; Section 1557 of the Patient Protection and Affordable Care Act, 42 U.S.C. § 18116; Title II of the Americans with Disability Act, 42 U.S.C. § 12131 et seq.; Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 701 et seq.; Section 508 of the Rehabilitation Act, 29 U.S.C. § 794d; the Age Discrimination Act of 1975, 42 U.S.C. 6101 et seq.; Title IX of the Education Amendments of 1972, 20 U.S.C. § 1681 et seq.

¹² One set of principles roots data privacy protection in international human rights law. *See* Electronic Frontier Foundation, *13 International Principles on the Application of Human Rights to Communication Surveillance* (last visited Sept. 27, 2022), <https://www.eff.org/document/13-international-principles-application-human-rights-communication-surveillance>. While data privacy is important everywhere, European law tends to be much stronger around data privacy, which allows for more successful advocacy centered on this axis.

¹³ *See* Deborah Hellman, *Measuring Algorithmic Fairness*, 106 VA. L. REV. 811 (2020) (discussing the problems with seeking algorithmic fairness in seeking something that produces the same number of false negatives and false positives for each group at issue and how to analyze which to prioritize); *see also, supra* note 5.

¹⁴ *See, e.g.*, AHRQ, *Impact of Healthcare Algorithms on Racial and Ethnic Disparities in Health and Healthcare Draft Comments* (Feb. 9, 2023), <https://effectivehealthcare.ahrq.gov/products/racial-disparities-health-healthcare/draft-report>; Hannah E Knight et al., *Challenging Racism in the Use of Health Data*, 3 THE LANCET E144 (Mar. 1, 2021), [https://www.thelancet.com/journals/landig/article/PIIS2589-7500\(21\)00019-4/fulltext](https://www.thelancet.com/journals/landig/article/PIIS2589-7500(21)00019-4/fulltext) (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); 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 for use as proxies for immutable characteristics that may be protected classes, other issues of discrimination in algorithms, and problems related to transparency); 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>.

¹⁵ *See, e.g.*, AHRQ *supra* note 14, at 43; Trevan Locke et al., Duke-Margolis Ctr. for Health Policy, *Preventing Bias and Inequities in AI-enabled Health Tools* (2022),

https://healthpolicy.duke.edu/sites/default/files/2022-07/Preventing%20Bias%20and%20Inequities%20in%20AI-Enabled%20Health%20Tools_1.pdf.

¹⁶ See, e.g., Edwards, *NIST Comments*, *supra* note 8.

¹⁷ 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).

¹⁸ Beneficiary compensation would include paying for transportation, lodging, childcare, and time served as an advisor.

¹⁹ Benefits Tech Advocacy Hub, *Missouri Medicaid Home and Community Based Services Eligibility Issues*, <https://www.btah.org/case-study/missouri-medicaid-home-and-community-based-services-eligibility-issues.html> (last visited Sept. 19, 2022).

²⁰ The widely used InterRAI HomeCare tool, which is adapted from a nursing facility assessment, is used for Medicaid level of care assessments and allocation of home and community-based services. Some states have used resource allocation data based largely on numbers derived from studies of home care delivered in Ontario, Canada in 2002. Machledt, *Medicaid Assessments for Long-Term Supports & Services (LTSS)* *supra* note 6; Machledt, *Evaluating Functional Assessments for Older Adults*, *supra* note 6.

²¹ See Kate Crawford & Jason Schultz, *AI Systems as State Actors*, 119 COLUMBIA L. REV. 1941 (2019), <https://columbialawreview.org/content/ai-systems-as-state-actors>; *Ark. Dept. of Commerce, Div. of Workforce Servs. v. Legal Aid of Ark.*, 645 S.W.3d 9 (S.C. Ark. 2022) (finding that unemployment claimants are not competitors for the purpose of the proprietary information exception and granting access to algorithm and related information requested through freedom of information act request to state); *Salazar v. Dist. of Columbia*, 596 F. Supp. 2d 67 (D.D.C. Feb. 6, 2009) (copyright law and local trade secret laws do not trump the federal Medicaid statute and regulations); see also *Waldrop v. New Mexico Dept. Human Servs.*, Civ. No. 14-047, 2015 WL 13665460 at *13 (D.N.M. Mar. 10, 2015) (discussing Medicaid beneficiaries right to information about processes and procedures used to determine services).

²² See, e.g., 42 U.S.C. § 18083.

²³ 42 U.S.C. § 18083(b)(1)(A)(iv); see also 42 C.F.R. § 435.902 (requiring that for Medicaid eligibility, "The agency's policies and procedures must ensure that the eligibility is determined in a manner consistent with simplicity of administration and the best interests of the applicant or beneficiary").

²⁴ Title VI of the Civil Rights Act of 1964, 42 U.S.C. § 2000d et seq.; Section 1557 of the Patient Protection and Affordable Care Act, 42 U.S.C. § 18116; Title II of the Americans with Disability Act, 42 U.S.C. § 12131 et seq.; Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 701 et seq.; Section 508 of the Rehabilitation Act, 29 U.S.C. § 794d.

²⁵ Worldwide Web Consortium (W3C), *Web Content Accessibility Guidelines (WCAG) 2.1* (June 5, 2018), <https://www.w3.org/TR/WCAG21/#background-on-wcag-2>.

²⁶ See Benefits Tech Advocacy Hub, *Florida Unemployment Insurance False Fraud Determinations*, <https://www.btah.org/case-study/florida-unemployment-insurance-false-fraud-determinations.html> (last visited Sept. 15, 2022).

²⁷ See, e.g., Youdelman et al., *supra* note 8 (describing problems with clinical algorithms and biased data); Edwards, *supra* note 8 (discussing institutional bias in health care).

²⁸ Amer. Assoc. on Intellectual & Developmental Disabilities, Frequently Asked Questions: SIS FAQ, <https://www.aaid.org/sis/faqs> (last visited Sept. 27, 2022).

²⁹ See, e.g., 42 C.F.R. 441.301(c)(2)(v).

³⁰ Jane Perkins, Nat'l Health L. Program, *Demanding Ascertainable Standards: Medicaid as a Case Study*, 2016 CLEARINGHOUSE REV. 1 (2016), <https://healthlaw.org/resource/demanding-ascertainable-standards-medicare-as-a-case-study/> (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); see also Nat'l Health L. Program, *L.S. by and through Ron S. v. Delia*, Eastern District of North Carolina and Fourth Circuit Court of Appeals (June 11, 2021), <https://healthlaw.org/resource/l-s-by-and-through-ron-s-v-delia-eastern-district-of-north-carolina-and-fourth-circuit-court-of-appeals/> (discussing the subsequent enforcement action of *Biggs v. Cohen* after the SIS was implemented statewide); Disability Rights NC, Cases and Reports, *Samantha R. v. State of North Carolina*, <https://disabilityrightsn.org/what-we-do/cases-and-reports/> (including allegations about the use of the SIS and underfunding services).

³¹ See, e.g., Evan McCormick, *What Happened When a "Wildly Irrational" Algorithm Made Crucial Healthcare Decisions*, THE GUARDIAN (July 2, 2021), <https://www.theguardian.com/us-news/2021/jul/02/algorithm-crucial-healthcare-decisions>; Benefits Tech Advocacy Hub, *Arkansas Medicaid Home and Community Based Services Hours Cuts*, <https://www.btah.org/case-study/arkansas-medicare-home-and-community-based-services-hours-cuts.html> (last visited Sept. 15, 2022).

³² Benefits Tech Advocacy Hub, *Wisconsin*, *supra* note 4.

³³ See, e.g., *Wit v. United Behavioral Healthcare*, 14-cv-2346-JCS, 2019 WL 1033730 (N.D. Cal. July 27, 2020), *aff'd in part, rev'd in part and remanded*, 58 F. 4th 1080 (9th Cir. 2023), and *rev'd*, no. 20-17363, 2022 WL 850647 (9th Cir. Mar. 22, 2022), *opinion withdrawn on denial of reh'g*, No. 20-17363, 2023 WL 446880 (9th Cir. 26, 2023), and *aff'd in part, rev'd in part and remanded*, 58 F.4th 1080 (9th Cir. 2023) (although not explicitly an ADS, discovery into utilization management tools found that the criteria used did not align with clinically accepted criteria and was unduly influenced by fiscal rationales); see also The Kennedy Forum, *A Breakdown of United Healthcare's Recent Parity Settlements* (Aug. 24, 2021) (detailing settlements of parity violations, including the improper use of an algorithm to trigger utilization review and subsequent denial of behavioral health claims).

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³⁵ Ibram x. Kendi, *There is No Such Thing as Race in Health-care Algorithms*, 1 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), <https://www.nejm.org/doi/full/10.1056/NEJMp1609535>.

³⁶ See, e.g., Hannah E Knight et al., *Challenging Racism in the Use of Health Data*, 3 THE LANCET E144 (Mar. 1, 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).

- ³⁷ 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).
- ³⁸ See 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> (describing opportunities for bias and human influence throughout the development of technology).
- ³⁹ *Id.*
- ⁴⁰ Laleh Seyyed-Kalantari et al., *Underdiagnosis Bias of Artificial Intelligence Algorithms Applied to Chest Radiographs in Underserved Patient Populations*, 27 NATURE MED. 2176 (2021).
- ⁴¹ Perkins, *Q&A: Using Assessment Tools to Decide Medicaid Coverage*, *supra* note 6; Perkins, *Ensuring that Assessment Tools are Available to Enrollees*, *supra* note 6; Machledt, *Medicaid Assessments for Long-Term Supports & Services (LTSS)*, *supra* note 6; Machledt, *Evaluating Functional Assessments for Older Adults*, *supra* note 6.
- ⁴² Emmanuel Moss et al., Data & Society, *Assembling Accountability: Algorithmic Impact Assessment for the Public Interest*, (June 29, 2021), <https://datasociety.net/library/assembling-accountability-algorithmic-impact-assessment-for-the-public-interest/>; Aaron Rieke et al., *supra* note 38.
- ⁴³ Nat'l Council on Disabilities, *Quality-Adjusted Life Years and the Devaluation of Life with Disability: Part of the Bioethics and Disability Series* (Nov. 2019), https://ncd.gov/sites/default/files/NCD_Quality_Adjusted_Life_Report_508.pdf.
- ⁴⁴ *Supra* note 5.
- ⁴⁵ Madeline B. Deutsch et al., *Electronic Health Records and Transgender Patients—Practical Recommendations for the Collection of Gender Identity Data*, 30 J. GEN. INTERNAL MED. 843 (2014).
- ⁴⁶ 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>.
- ⁴⁷ Wyatt Koma et al., Kaiser Fam. Found., *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/>.
- ⁴⁸ Jason Hiner, C-Net, *Why Tech Made Racial Injustice Worse, and How to Fix It*, (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., Data & Society, *Good Intentions, Bad Inventions: The Four Myths of Healthy Tech* (Oct 2020), <https://datasociety.net/wp-content/uploads/2020/10/Healthy-Tech-Myths-DataSociety-20201007.pdf>.
- ⁴⁹ See, e.g. Molly Hennessy-Fiske, *Texas Attorney General's Office Sought State Data on Transgender Texans*, WASH. POST (Dec. 14, 2022), <https://www.washingtonpost.com/nation/2022/12/14/texas-transgender-data-paxton/>.

⁵⁰ Naomi Goldberg, Movement Advancement Project, *Administrative Data: Providing Information to Advance Autonomy and Drive Equality*, (Feb. 2023), <https://healthlaw.org/wp-content/uploads/2023/02/Drive-Equality-MAP-NHeLP-Jan2023-2.pdf>.

⁵¹ For example, Medicaid applications must verify an applicant's sex or gender in order to complete the eligibility determination. Most Medicaid applications among states only ask whether the applicant is "male" or "female" despite the fact that some applicants are transgender, non-binary, or another gender identity that does not fit within either binary category on the application. California is no exception, although California's state Medicaid agency is seeking approval from CMS to include a more inclusive sex/gender question with SOGISC data questions in their single streamlined application (SSApp). See Cal. Dept. Health Care Services, *CA - Submission Package - CA2021MS00080 - (CA-22-0007) - Eligibility* (Mar. 14, 2022), <https://www.dhcs.ca.gov/formsandpubs/laws/Documents/SPA-22-0007.pdf>. However, there are approximately 12 Medicaid managed care plans in California with NCQA accreditation to measure quality performance and consumer experience measures by collecting data, including SOGISC data, to address health disparities. Since California's SSApp only asks applicants if they are "male" or "female", managed care plans struggle to accurately capture the nuanced gender demographics of their members when they receive case information data from the agency. This creates barriers for accredited health plans to identify and reach out to the at-risk populations they're trying to help, such as transgender men in need of pap smears or pregnancy-related services, to inform them about plan benefits tailored to their health needs. Such data shortcomings perpetuate health disparities.

⁵² Nat'l Acad. of Scis., Eng'g & Med., *Measuring Sex, Gender Identity, and Sexual Orientation*. Washington, DC: The National Academies Press (2022), <https://doi.org/10.17226/26424>.

⁵³ Nat'l. Sci. & Tech. Council Subcomm. on Equitable Data, *Federal Evidence Agenda on LGBTQI+ Equity*, 37 (Jan. 2023), <https://www.whitehouse.gov/wp-content/uploads/2023/01/Federal-Evidence-Agenda-on-LGBTQI-Equity.pdf>.

⁵⁴ Fed. Comm. on Statistical Methodology, *Data Protection Toolkit: Report and Resources on Statistical Disclosure Limitation Methodology and Tiered Data Access* (Nov. 28, 2022), <https://nces.ed.gov/fcsm/dpt>.

⁵⁵ Mary Lou Breslin & Silvia Yee, Disability Rights Educ. & Defense Fund, *This Data Not That Data: Big Data, Privacy, and the Impact on People with Disabilities* (2023), <https://healthlaw.org/resource/risks-and-rewards-of-demographic-data-collection-how-effective-data-privacy-can-promote-health-equity/>.

⁵⁶ Machledt, *Medicaid Assessments for Long-Term Supports & Services (LTSS)*, *supra* note 6.

⁵⁷ See, e.g., Medicaid Matters NY & NY Chapter Nat'l Ass'n. Elder Law Attys., *Mis-Managed Care: Fair Hearing Decisions on Medicaid Home Care Reductions by Managed Long Term Care Plans* June-December 2015, 4 (July 2016), <https://medicaidmattersny.org/mltc-report/>.

⁵⁸ Vicki Lens, *Welfare and Work Sanctions: Examining Discretion on the Front Lines*, 82 SOC. SERV. REV. 1999 (2008).

⁵⁹ Human Servs. Rsch. Inst., *My Life, My Community! Re-designing Supports for Virginians with Intellectual and Developmental Disabilities Project Report* (Nov. 2013).

⁶⁰ Ryan Calo & Danielle Keats Citron, *The Automated Administrative State: A Crisis of Legitimacy* 70 EMORY L. J. 797 (2021), <https://scholarlycommons.law.emory.edu/cgi/viewcontent.cgi?article=1418&context=elj>.

⁶¹ Adil H. Haider, Eric B. Schneider & Lisa M. Kodadek, *Emergency Department Query for Patient-Centered Approaches to Sexual Orientation and Gender Identity: The EQUALITY Study*, 177 JAMA INTERNAL MED. 819 (2017).

⁶² See, e.g., Maria Agustina Ricci Lara, Rodrigo Echeveste & Enzo Ferrante, *Addressing Fairness in Artificial Intelligence for Medical Imaging*, NATURE COMMUNICATIONS (Aug. 6, 2022), <https://www.nature.com/articles/s41467-022-32186-3>.

⁶³ See, e.g., N.C. Dep't Health & Human Servs., LME-MCO Communication Bulletin J297: LME-MCO, *L.S. v. Wos* Instruction (July 13, 2018), <https://files.nc.gov/ncdhhs/Joint-Communication-Bulletin--J297--LME-MCO-LS-V-Wos-Instruction--002-.pdf> (instructing managed care plans on how assessments results can and cannot be used in the person centered planning process); Perkins *supra* note 30 (discussing the initial case that led to this guidance).