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**COMMENTS OF THE CENTER ON PRIVACY & TECHNOLOGY AT  
GEORGETOWN LAW and UPTURN  
to U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
on PROPOSED RULE ON DISABILITY DISCRIMINATION (RIN 0945-AA15)  
*Submitted November 13, 2023***

The Center on Privacy & Technology at Georgetown Law and Upturn submit the following comments regarding the Department of Health & Human Services' proposed rule on Discrimination on the Basis of Disability in Health and Human Service Programs or Activities, largely in response to "Child Welfare Question 2." For the reasons that follow, we believe the proposed list of prohibited activities is incomplete because it fails to address the front end of the system. We are particularly concerned with discrimination that arises in two contexts:

- (1) **Reporting.** Department recipients in medical, mental health, social services, education, or other sectors make up an integral part of the child welfare system. HHS should clarify that they may violate federal antidiscrimination law by reporting families to child welfare authorities on the basis of speculation, stereotypes, or generalizations about their disabilities; and
- (2) **Screening and Investigation.** Agencies determine which reports warrant investigation and conduct investigations in accordance with federal law. Disability discrimination may arise at this stage, especially as agencies move to adopt data-driven tools that incorporate disability data in discriminatory ways.

Federal guidance on the issues raised in the proposed rule is welcome and necessary. But without careful attention to the wide open front door of the system, HHS's proposed rule will fail to reach the source of many families' experiences of discrimination.

**I. THE DEPARTMENT CANNOT ADDRESS DISABILITY DISCRIMINATION IN THE CHILD WELFARE SYSTEM WITHOUT ADDRESSING THE WAYS THE SYSTEM SWEEPS FAMILIES IN.**

In line with Section 504’s comprehensive mandate, proposed § 84.60(a) seeks to prohibit all forms of discrimination against persons with disabilities in the child welfare system. The prohibitions currently listed under proposed § 84.60(b), however, risk arbitrarily limiting those protections to families already deeply enmeshed with the system, addressing only decisions about removing children from their families, terminating parental rights, and accessing services and programming provided by the system. But most encounters with the system occur well before these points, and there are many opportunities for discrimination to occur during families’ early interactions with system actors—at the reporting, screening, and investigation stages. Although the prohibitions articulated in proposed paragraph (b) are identified as “not exhaustive, but rather, illustrative,”<sup>1</sup> the proposed provision’s silence on front-end activities renders its list of prohibited conduct woefully incomplete and the rule subject to misinterpretation.

The child welfare system is often described in reference to the numbers of children in foster care at any given time. Recent years have seen this figure hover at around 400,000 children.<sup>2</sup> This number, however, fails to capture the true scope and impact of the system. Each year from 2016 to 2021, Child Protective Services (CPS) agencies across the nation received approximately four million referrals, touching the lives of more than seven million children.<sup>3</sup> CPS screened in for investigation more than two million of these referrals,<sup>4</sup> triggering investigations of approximately 3.5 million children’s families each year.<sup>5</sup> In 2019 in New York alone, more than 84,000 children experienced

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<sup>1</sup> Discrimination on the Basis of Disability in Health and Human Service Programs or Activities, 88 Fed. Reg. 63392, 63417 (Sept. 14, 2023).

<sup>2</sup> AFCARS Report #29, Adoption and Foster Care Analysis Reporting System (June 27, 2023), <https://www.acf.hhs.gov/sites/default/files/documents/cb/afcars-report-29.pdf>, at 1.

<sup>3</sup> CHILDREN’S BUREAU, CHILD MALTREATMENT 2021 8 (2023) <https://www.acf.hhs.gov/sites/default/files/documents/cb/cm2021.pdf> [hereinafter CHILD MALTREATMENT 2021]; CHILDREN’S BUREAU, CHILD MALTREATMENT 2020 8 (2022), [https://www.acf.hhs.gov/sites/default/files/documents/cb/child-maltreatment-report-2020\\_0.pdf](https://www.acf.hhs.gov/sites/default/files/documents/cb/child-maltreatment-report-2020_0.pdf).

<sup>4</sup> CHILD MALTREATMENT 2021 at 8.

<sup>5</sup> DOROTHY ROBERTS, TORN APART: HOW THE CHILD WELFARE SYSTEM DESTROYS BLACK FAMILIES AND HOW ABOLITION CAN BUILD A SAFE WORLD 162 (Basic Books 2022).

investigations from the city’s Administration for Children’s Services.<sup>6</sup> In 2018, Los Angeles County received “225,000 calls . . . to [its] child protection hotline, resulting in the investigation of 137,000 allegations.”<sup>7</sup> A 2021 study looking at data from the 20 most populous U.S. counties found that roughly one in every three children will have a CPS investigation during their childhood.<sup>8</sup> Black children are particularly likely to experience an investigation, with rates as high as 62.8%.<sup>9</sup>

In order to meaningfully address the harms of discrimination in the child welfare system, the Department must engage with the “modal” family policing encounter: reporting, investigation, and supervision.<sup>10</sup>

**A. *The Department must specifically address disability discrimination at the reporting stage.***

The system’s disparate treatment of individuals with disabilities begins long before a case is filed in court or a removal is contemplated: it begins with surveillance and reporting.<sup>11</sup> A vast network of professionals across fields such as social services, “healthcare, education, and law enforcement” have been deputized by mandatory

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<sup>6</sup> *See id.*

<sup>7</sup> Scott Schwebke, *Audit finds LA County Family Services failing to protect children from abuse*, L.A. Daily News (May 21, 2019), <https://www.dailynews.com/2019/05/21/la-county-dcfs-failing-to-protect-children-from-abuse-state-auditors-find/>.

<sup>8</sup> *See* FRANK EDWARDS ET AL., CONTACT WITH CHILD PROTECTIVE SERVICES IS PERVASIVE BUT UNEQUALLY DISTRIBUTED BY RACE AND ETHNICITY IN LARGE US COUNTIES (2021), <https://www.pnas.org/doi/epdf/10.1073/pnas.2106272118>.

<sup>9</sup> *See id.* The counties surveyed in the study had investigation rates ranging from 32.9% to 62.8% for Black children. That means that even at the low end, one third of all Black families could expect to experience an investigation. Rates for other groups hovered around twenty percent. *Id.*

<sup>10</sup> *See* J. Khadijah Abdurahman, *Calculating the Souls of Black Folks: Predictive Analytics in the New York City Administration for Children’s Services*, 11 Colum. Race & L. Forum 75, 91 (2021).

<sup>11</sup> *See, e.g.,* Rebecca Rebbe et al., *Prevalence of Births and Interactions with Child Protective Services of Children Born to Mothers Diagnosed with an Intellectual and/or Developmental Disability*, 25 Maternal Child Health J. 626 (2021); Robyn Powell, *Achieving Justice for Disabled Parents and Their Children: An Abolitionist Approach*, 33 Yale J.L. & Feminism 37, 62 (2022); Sarah Lorr, *Disabling Families*, 76 Stanford L. Rev. \_\_\_, 16 (forthcoming 2024); *see also* VIRGINIA EUBANKS, AUTOMATING INEQUALITY 181 (2019) (“[C]lassification and criminalization work by including poor and working-class people in systems that limit their rights and deny their basic human needs. The digital poorhouse doesn’t just exclude, it sweeps millions of people into a system of control that compromises their humanity and their self-determination.”).

reporting laws to act as the system’s eyes and ears.<sup>12</sup> Together, they serve as an “expansive monitoring apparatus that disproportionately scrutinizes marginalized families, including those with disabled parents.”<sup>13</sup> HHS has jurisdiction over many of the entities that contribute to this surveillance and reporting, and should, through this rulemaking process, address this “front door” to the system. The current proposed rule does not clearly do so. Without attention to the ways that parents with disabilities are disproportionately referred in to the system, the rule’s goals cannot be realized.<sup>14</sup>

Numerous studies have documented that parents with disabilities “have higher rates of child welfare involvement and worse outcomes than their non-disabled peers,” and that this disparate impact starts with “initial referrals to child welfare.”<sup>15</sup> For example, a 2019

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<sup>12</sup> Victoria Copeland, The Stop LAPD Spying Coalition, & Downtown Women’s Action Coalition, *DCF(S) Stands For Dividing and Conquering Families”: How the Family Policing System Contributes to the Stalker State*, available at <https://stoplapdspying.org/wp-content/uploads/2023/05/Dividing-and-Conquering-Families.pdf>; see also Robyn M. Powell, *Under the Watchful Eye of All: Disabled Parents and the Family Policing System’s Web of Surveillance*, 112 Calif. L. Rev. \_\_\_, 33 (forthcoming 2024). Indeed, many affected families and advocates have begun referring to the system as the “family policing system,” in an effort to “more accurately describe[] the system’s use of surveillance, regulation, and punishment to oppress families and communities, the majority of which are Black or Brown and low-income.” Glossary of Terms, Center for Family Representation, <https://cfrny.org/glossary-of-terms/>. “The term ‘family policing system’ was first used by Victoria Copeland and Brianna Harvey in July 2020. Copeland and Harvey were doctoral students of Dorothy Roberts at the time, and the term was later adopted by Roberts and the broader movement.” *Id.*

<sup>13</sup> See Powell, *Under the Watchful Eye*, *supra* note 12, at 33 (quoting Mike Hixenbaugh, Suzy Khimm, & Agnel Philip, *Mandatory Reporting Was Supposed to Stop Severe Child Abuse. It Punishes Poor Families Instead.*, PROPUBLICA (Oct. 12, 2022), <https://www.propublica.org/article/mandatory-reporting-strains-systems-punishes-poor-families>).

<sup>14</sup> See Nancy R. Mudrick & Carrie Jefferson Smith, *Commentary, Mandatory Reporting for Child Protection in Health Settings and the Rights of Parents with Disabilities*, 10 Disability & Health J. 165, 166 (2017) (noting that the “August 2015 DOJ/HHS document affirms the applicability of the ADA and 504” to “public child welfare” processes, but arguing that “risk remains as long as those who launch an investigation through a report of potential abuse or neglect continue to do so with the parent’s disability as the primary indicator”).

<sup>15</sup> Sharyn DeZelar & Elizabeth Lightfoot, *Who refers parents with intellectual disabilities to the child welfare system? An analysis of referral sources and substantiation*, 119 Child. & Youth Servs. Rev. 105639 (2020); see also Powell, *Under the Watchful Eye*, *supra* note 12, at 43 n.224 (collecting sources that “overwhelmingly shows that parents with intellectual or psychiatric disabilities are more likely to be referred to the family policing system.”); *Id.* at 43-44 (“mothers with intellectual disabilities see dramatically higher reporting rates to the family policing system soon after giving birth compared to mothers without disabilities” (citing Rebbe et al., *supra* note 11, at 629)).

national survey found that “parents with psychiatric disabilities were eight times more likely to have contact” with the system than parents without a disability.<sup>16</sup> A study of administrative data from Washington State found that “twenty-two percent of mothers with intellectual or developmental disabilities were the subject of a report to the family policing system within one year of birth and thirty-seven percent within four years,” compared to just “six percent of mothers without intellectual disabilities . . . within one year of birth and only ten percent within four years.”<sup>17</sup>

The harm that families with disabilities experience through their encounters with the system is intersectional. For example, parents “who had a disability label in their school records are . . . more than twice as likely to have child welfare involvement than their peers without such a label.”<sup>18</sup> And Black children are far more likely to have such labels applied in school.<sup>19</sup> Parents with disabilities are also “much more likely than others to be poor.”<sup>20</sup> It is well-documented that vague neglect standards often conflate neglect with poverty.<sup>21</sup>

One explanation commonly offered for the higher rates of referral among parents with disabilities is that these parents are exposed more frequently to mandated reporters.<sup>22</sup> These professionals are responsible for the vast majority of referrals nationwide.<sup>23</sup>

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<sup>16</sup> Robyn Powell, *Achieving Justice for Disabled Parents and Their Children: An Abolitionist Approach*, 33 *Yale J. L. & Feminism* 37, 62 (2022) (citing Katy Kaplan et al., *Child Protective Service Disparities and Serious Mental Illnesses: Results from a National Survey*, 70 *Psychiatric Services* 202, 204 (2019)).

<sup>17</sup> *Id.* at 62 (citing Rebbe et al. at 629).

<sup>18</sup> NAT’L COUNCIL ON DISABILITY, *ROCKING THE CRADLE: ENSURING THE RIGHTS OF PARENTS WITH DISABILITIES AND THEIR CHILDREN* 77-78 (2012), [https://www.ncd.gov/sites/default/files/Documents/NCD\\_Parenting\\_508\\_0.pdf](https://www.ncd.gov/sites/default/files/Documents/NCD_Parenting_508_0.pdf).

<sup>19</sup> Sarah H. Lorr, *Unaccommodated: How the ADA Fails Parents*, 110 *Cal. L. Rev.* 1315, 1328 (2022) (“the disproportionate inclusion of Black children in special education portends their eventual treatment in the family regulation system”).

<sup>20</sup> Elspeth Slayter & Robyn Powell, *An Overview of Disabled Children and Parents in the Family Policing System*, in *SOCIAL WORK PRACTICE AND DISABILITY COMMUNITIES: AN INTERSECTIONAL ANTI-OPPRESSIVE APPROACH* (“the framing of poverty as neglect has led to many families being unnecessarily subjected to the family policing system”).

<sup>21</sup> See, e.g., Jerry Milner & David Kelly, *It’s Time to Stop Confusing Poverty with Neglect*, *THE IMPRINT* (Jan. 17, 2020), <https://imprintnews.org/child-welfare-2/time-for-child-welfare-system-to-stop-confusing-poverty-with-neglect/40222>.

<sup>22</sup> See DeZelar & Lightfoot, *supra* note 15, at 4.

<sup>23</sup> See *CHILD MALTREATMENT 2021 supra* note 4, at 9.

According to the most recent data available through the Children’s Bureau’s Child Maltreatment report, professionals such as law enforcement, education, medical, social services, and mental health personnel accounted for 67% of all screened-in reports in 2021.<sup>24</sup> Researchers have found that “[r]ates of investigations stemming from medical professionals’ reports increased faster than did rates for other mandated reporters.”<sup>25</sup>

These professionals may be “mandated” to report suspicions of child maltreatment to authorities under federal and state law, but they make decisions about when to report based on subjective judgments. To receive federal funding under the Child Abuse Prevention and Treatment Act (CAPTA), federal law requires states to have “provisions or procedures for an individual to report known and suspected instances of child abuse and neglect,” including mandatory reporting laws.<sup>26</sup> All U.S. states (as well as the District of Columbia, American Samoa, Guam, the Northern Mariana Islands, Puerto Rico, and the U.S. Virgin Islands) have such laws.<sup>27</sup> The details vary somewhat state to state, but the laws generally require professionals to make a report “when the reporter, in his or her official capacity, suspects or has reason to believe that a child has been abused or neglected,” or when the “reporter has knowledge of, or observes a child being subjected to, conditions that would reasonably result in harm to the child.”<sup>28</sup> Each of these standards includes discretion: reporters usually must assess whether they in fact have “reason to believe” or “knowledge” of suspected maltreatment, whether the observed conditions would “reasonably” result in harm to the child, and what supports or interventions to mitigate or eliminate any suspected risks are available to the family absent a report.<sup>29</sup> Professionals with information about a family must therefore use their judgment to assess whether the information they have indeed requires them to report.

Too often, assumptions and biases about parents with disabilities influence these decisions. To the extent a recipient makes a report on the basis of such assumptions and biases, this act alone may constitute unlawful disability discrimination under Section 504. HHS should take this opportunity to clarify that it does. Section 504 provides that

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<sup>24</sup> *See id.*

<sup>25</sup> Frank Edwards et al., *Medical Professional Reports and Child Welfare System Infant Investigations: An Analysis of National Child Abuse and Neglect Data System Data*, 7 *Health Equity* 653, 653 (2023).

<sup>26</sup> 42 U.S.C. § 5106a(b)(2)(B)(i).

<sup>27</sup> CHILDREN’S BUREAU, MANDATORY REPORTERS OF CHILD ABUSE AND NEGLECT 1 (2019), <https://www.childwelfare.gov/pubPDFs/manda.pdf>.

<sup>28</sup> *Id.*

<sup>29</sup> *See id.* at 4.

“[n]o otherwise qualified individual with a disability . . . , shall, solely by reason of her or his disability, . . . be subjected to discrimination under any program or activity receiving Federal financial assistance.” Biased reporting of individuals with disabilities is just such discrimination. A few case examples from states around the country help to illustrate what parents with disabilities may experience:

*California:* One mother described her daughter’s experience as a parent in the system:

*My daughter is diagnosed um, um, schizoaffective. So because she's diagnosed schizoaffective they already judged her. They say she was retarded she can't handle nothing. So they literally put in a report that my daughter was hallucinating. And they went after my granddaughter tooth and nail, the whole three years. [...] And my daughter didn't have any teeth, stereotyping her, 'oh you've been on drugs all your life you don't have no teeth. No my daughter have no teeth because she had gingivitis, she has a gum disease, that's why she has no teeth. Not that that has anything to do with my granddaughter.’<sup>30</sup>*

*Florida:* Florida mother Alysha Princess Cesaire, who has a physical disability that “causes her to use a walker and have difficulty speaking,” gave birth to her son at Hollywood, Florida’s Memorial Regional Hospital on February 1, 2018.<sup>31</sup> Due to her disability, a worker at the hospital “phoned the state’s child abuse hotline to express concerns that Cesaire’s physical disability . . . rendered her an unfit mother.”<sup>32</sup>

*Missouri:* In Kansas City, Missouri, a nurse called in a report “because the parents were both legally blind.”<sup>33</sup> The parents spent the first hours after their baby’s birth “being questioned by a child protective services worker,” and were forced to leave the hospital without their infant daughter.<sup>34</sup> No one made any allegations of abuse or neglect. The family was ultimately reunited, but the “baby and parents were deprived of the bonding that occurs during the first two months of life.”<sup>35</sup>

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<sup>30</sup> See Copeland, et al., *supra* note 12.

<sup>31</sup> Carol Marbin Miller, *Florida Seized a Disabled Mom's 4-Day-Old Son: 'I Didn't Think This Could Happen in America'*, MIAMI HERALD (Feb. 10, 2022)

<https://www.miamiherald.com/news/health-care/article258155053.html>.

<sup>32</sup> *Id.*; see also Powell, *Under the Watchful Eye*, *supra* note 12.

<sup>33</sup> Nancy R. Mudrick & Carrie Jefferson Smith, *Commentary, Mandatory Reporting for Child Protection in Health Settings and the Rights of Parents with Disabilities*, 10 *Disability & Health J.* 165, 167 (2017).

<sup>34</sup> *Id.*

<sup>35</sup> *Id.*

*New York*: Parents subjected to investigations and family separations at the hands of New York City’s Administration for Children’s Services (NYCACS) brought suit in 2017 alleging that NYCACS had discriminated against them on the basis of their disabilities or perceived disabilities.<sup>36</sup> In their complaint, these parents documented a number of reports of suspected child maltreatment in which assumptions about their disabilities were foundational. The complaint alleged, for example, that a hospital social worker called in a report relating to one named plaintiff, alleging that she “had an intellectual disability which impaired her ability to parent [her child] and that she needed assistance.”<sup>37</sup> As to another named plaintiff, the complaint alleged that a “preventive worker at Catholic Charities called in a new report to the [State Central Registry], which specifically identified [the plaintiff] as having ‘mental delays.’”<sup>38</sup> NYCACS deemed that allegation unfounded and did not refer the plaintiff to any services tailored to her disability. Nonetheless, NYCACS then later itself initiated a new report and investigation into the same plaintiff alleging in its report, without basis, that “she suffered from ‘developmental delays’ that impair[ed] her ability to provide care for [her child].”<sup>39</sup>

These are just a few examples. There are many more.<sup>40</sup>

The Department has an opportunity with this proposed rulemaking to clarify recipients’ obligations under federal law and work to reduce the harm of discrimination occurring at the start of families’ interactions with the system. HHS has jurisdiction over many of the professionals that make reports. For example, HHS funds many entities that provide medical and mental health treatment and social services, as well as some state and local

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<sup>36</sup> Complaint at 1-2, *Josefina S. et al. v. The City of New York*, No. 17-CV-7661 (S.D.N.Y. Oct. 6, 2017).

<sup>37</sup> *Id.* at 19.

<sup>38</sup> *Id.* at 25.

<sup>39</sup> *Id.*

<sup>40</sup> To the extent that the Department has received fewer complaints focused on the initial discriminatory report alone than other decision points in the system, that fact would not be surprising. At this early stage in a family’s interaction with the system, parents do not have a right to an attorney. Many parents subjected to discriminatory reports may never get to the point of consulting with an attorney. For example, a discriminatory report might cause the agency to investigate the family but never take the case to court. This investigation could itself be disruptive, burdensome, and stigmatizing to the family, but, without counsel, the individuals involved may have no idea that there is an avenue to raise a complaint to federal authorities.



entities providing educational services and classified as law enforcement.<sup>41</sup> Section 504 and existing HHS regulations define “[p]rogram or activity” to mean “*all* of the operations of” a recipient.<sup>42</sup> This includes the making of reports. In this NPRM, HHS already recognizes reporting as a “key decision point[] in the child welfare system” where discrimination and bias may impact families.<sup>43</sup> Its absence from the proposed rule text risks rendering the proposed rule woefully ineffective.

HHS should not confine itself to a narrow definition of the “child welfare system.” It should see the system as the expansive network that it truly is, and use this opportunity to clarify for potential reporters that making reports to child protective authorities on the basis of assumptions, biases, speculation, stereotypes, or generalizations about parents with disabilities violates federal law. Such an intervention has the potential to decrease the number of families that ever come to the attention of the system, saving them the trauma, burden, and stigma of an investigation, and reducing the likelihood that children will unnecessarily be separated from their parents.

***B. The Department must specifically address disability discrimination at the screening and investigation stages, including through data-driven tools.***

Once authorities receive a report alleging child maltreatment, they are again more likely to investigate and substantiate cases against parents with disabilities.<sup>44</sup> In one recent study, parents with any type of disability had “70% higher odds of substantiation than parents without disabilities.”<sup>45</sup> Research also suggests that parents with intellectual disabilities (“ID”) are particularly at risk: a study based on NCANDS data found parents with ID had a 73% higher likelihood of having their case substantiated than a parent with no disability.<sup>46</sup> This disproportionality rate was “higher than parents with disability diagnoses of learning disability, physical disability, visual/hearing impairment and other

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<sup>41</sup> See, e.g., 88 Fed. Reg. 63392, 63395 (“The Department funds a wide array of programs and activities in which recipients make decisions regarding medical treatment.”); Montgomery County Public Schools:1108631 [23-004845] Patient Tutoring Services, PIID 75N90023P00306 (funding award to Montgomery County, Maryland Board of Education); Tracking Accountability in Government Grants System, <https://taggs.hhs.gov/SearchRecip> (listing 143 entities under the “Recipient Type” “Law Enforcement Agency”).

<sup>42</sup> 29 U.S.C. 794(b)(1)(A); 45 C.F.R. § 84.3 (emphasis added).

<sup>43</sup> 88 Fed. Reg. 63392, 63411.

<sup>44</sup> See DeZelar & Lightfoot, *supra* note 15, at 4 (2020).

<sup>45</sup> *Id.*

<sup>46</sup> *Id.* at 2.

medical conditions, with only parents with severe mental illness or those with multiple disabilities having higher odds of substantiation than parents with ID.”<sup>47</sup>

Disability bias is also reflected in the data-driven tools on which agencies are relying to make decisions about cases. These tools combine information gathered by a hotline or case worker with historical data held by or accessible to the agency to help a worker calculate, or in some cases automatically calculate, a risk score or risk flag.<sup>48</sup> Historical data incorporated into these tools might include data from the child welfare system itself, demographic information, interactions with other social service and criminal legal system actors, and may include health and mental health data.<sup>49</sup>

These tools carry with them great potential for “algorithmic discrimination.”<sup>50</sup> They may import historical patterns of bias into present and future decisions, exacerbate inequalities, and harm protected classes through their use. Although disability and health diagnoses are often not indicative of an immediate or future safety concern that would result in harm to a child,<sup>51</sup> they may be factored into these tools in ways that increase a family’s cumulative risk score, pushing it over a threshold—for example, from screened out to screened in, or unfounded to substantiated—it may not otherwise have crossed.

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<sup>47</sup> *Id.*

<sup>48</sup> Chouldechova et al., *A case study of algorithm-assisted decision making in child maltreatment hotline screening decisions*, 81 *Proceedings of Machine Learning Research* 4 (2018).

<sup>49</sup> *Id.* at 3. See also Terry Luna, *CWS/CMS Referral Screening*, Central CA Training Academy, available at <https://chhs.fresnostate.edu/ccta/documents/booklets-referral-screening.pdf>, at 10; *CWS Policy Manual: Emergency Response – Hotline – Function and Procedure*, San Diego County, available at [https://www.sandiegocounty.gov/content/dam/sdc/hhsa/programs/cs/cws/policies/emergency\\_response/Hotline%20-%20Function%20and%20Procedure.pdf](https://www.sandiegocounty.gov/content/dam/sdc/hhsa/programs/cs/cws/policies/emergency_response/Hotline%20-%20Function%20and%20Procedure.pdf), at 2.

<sup>50</sup> Exec. Order No. 14,091, *Further Advancing Racial Equity and Support for Underserved Communities Through the Federal Government*, 88 Fed. Reg. 10825, 10832 (Feb. 16, 2023) (“The term ‘algorithmic discrimination’ refers to instances when automated systems contribute to unjustified different treatment or impacts disfavoring people based on their actual or perceived race, color, ethnicity, sex (including based on pregnancy, childbirth, and related conditions; gender identity; intersex status; and sexual orientation), religion, age, national origin, limited English proficiency, disability, veteran status, genetic information, or any other classification protected by law.”).

<sup>51</sup> See, e.g., ROCKING THE CRADLE, *supra* note 18, at 186; Lorr, *Unaccommodated*, *supra* note 19 at 1329 (citing Tim Booth & Wendy Booth, *Parenting with Learning Disabilities*, 23 *Brit. J. Soc. Work* 459, 461–63 (1993) (“On this point, however, the research evidence is consistent and persuasive. There is no clear relationship between parental competency and intelligence.”)).

The problem of algorithmic discrimination is not just present in child welfare algorithms, but has been documented across many fields. For example—and of particular relevance to this rulemaking process—medical providers have widely adopted a host of algorithmic tools used in treatment planning, supply chain, and revenue management. Some of these tools have been shown to, for example, “systematically privilege[] white patients over black patients”<sup>52</sup> and withhold care on the basis of “predictions,” as opposed to individualized factual assessments about patients’ relationships to opioids.<sup>53</sup>

HHS’s proposed rule should ensure that its prohibitions against disability discrimination apply equally to decisions shaped by data-driven tools as those made by humans alone. HHS should address this clearly in the proposed § 84.60 regarding child welfare, the proposed § 84.56 regarding the provision of medical care, and as appropriate elsewhere in the proposed rule.

To illustrate how data-driven tools contribute to discrimination in the child welfare context, we provide three case studies below of tools currently used by child welfare agencies around the country.

### **1. The Allegheny Family Screening Tool and its progeny**

Since approximately 2014, agencies across the country have begun incorporating a new generation of algorithmic and data-driven tools into their decision-making: what many refer to as “predictive analytics.”<sup>54</sup> According to an ACLU report, in 2021, at least 26 states and the District of Columbia have considered adopting such tools, and at least 11

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<sup>52</sup> Tom Simonite, *A Health Care Algorithm Offered Less Care to Black Patients*, *Wired* (Oct. 24, 2019), <https://www.wired.com/story/how-algorithm-favored-whites-over-blacks-health-care/>.

<sup>53</sup> See Maia Szalavitz, *The Pain Was Unbearable. So Why Did Doctors Turn Her Away?*, *Wired* (Aug. 11, 2021), <https://www.wired.com/story/opioid-drug-addiction-algorithm-chronic-pain/>.

<sup>54</sup> See, e.g., Anjana Samant, Aaron Horowitz, Kath Xu & Sophie Beiers, *Family Surveillance by Algorithm*, ACLU (Sept. 2021), <https://www.aclu.org/fact-sheet/family-surveillance-algorithm>; *The Allegheny Family Screening Tool*, Allegheny County, <https://www.alleghenycounty.us/Human-Services/News-Events/Accomplishments/Allegheny-Family-Screening-Tool.aspx>; RHEMA VAITHIANATHAN, IMPLEMENTING A CHILD WELFARE DECISION AIDE IN DOUGLAS COUNTY: METHODOLOGY REPORT (Dec. 2019), [https://csda.aut.ac.nz/\\_data/assets/pdf\\_file/0009/347715/Douglas-County-Methodology-Final-3-02-2020.pdf](https://csda.aut.ac.nz/_data/assets/pdf_file/0009/347715/Douglas-County-Methodology-Final-3-02-2020.pdf).

jurisdictions were already using them.<sup>55</sup> One of the first and most-discussed of these tools is the Allegheny Family Screening Tool (AFST), developed by Allegheny County’s Department of Human Services in partnership with a team “led by the co-director of the Centre for Social Data Analytics, Rhema Vaithianathan.”<sup>56</sup>

The AFST relies on “multiple data sources that contain[] direct and indirect references to disability-related information.”<sup>57</sup> For example, at least one version of the tool includes “features related to whether people involved with a referral have recorded diagnoses of various behavioral and mental health disorders that have been considered disabilities under the Americans with Disabilities Act (ADA),” as well as “features related to public benefits — such as Supplemental Security Income (SSI) benefits — that may be related to or potentially proxies for an individual’s disability status.”<sup>58</sup> Researchers have found that use of the AFST or similar tools can lead to discrimination against individuals with a disability, as well as against individuals by virtue of their association with a person with a disability:<sup>59</sup>

Because of the weights assigned to these three features in V2.1 and the binning procedure used to convert probabilities to AFST scores, being associated (through a referral) with people who have a disability and access services related to those disabilities — as encoded through these variables — can increase an individual’s AFST score by several points. This finding, discussed further in our Appendix A.2, is not just a theoretical possibility. In both the training data we reviewed and the production data from 2021, we identified several examples of individuals who had identical values for each feature considered by the model except for the indicator variable for

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<sup>55</sup> Anjana Samant, Aaron Horowitz, Sophie Beiers & Kath Xu, *Family Surveillance by Algorithm: The Rapidly Spreading Tools Few Have Heard Of*, ACLU (Sept. 29, 2021), <https://www.aclu.org/news/womens-rights/family-surveillance-by-algorithm-the-rapidly-spreading-tools-few-have-heard-of>.

<sup>56</sup> *The Allegheny Family Screening Tool*, *supra* note 55.

<sup>57</sup> Marissa Gerchick et al., *The Devil is in the Details: Interrogating Values Embedded in the Allegheny Family Screening Tool*, FAccT ‘23: Proceedings of the 2023 ACM Conf. Fairness, Accountability, & Transparency 1292, 1298 (June 2023), <https://doi.org/10.1145/3593013.3594081>.

<sup>58</sup> *Id.* at 1298.

<sup>59</sup> See, e.g., *McCullum v. Orlando Reg’l Healthcare Sys., Inc.*, 768 F.3d 1135, 1142 (11th Cir. 2014) (“It is widely accepted that under both the RA and the ADA, non-disabled individuals have standing to bring claims when they are injured because of their association with a disabled person.”).

whether the alleged “perpetrator” had any behavioral health history in the database. Among these matches, individuals with the behavioral health indicator had scores 0-3 points higher than those without the behavioral health indicator.<sup>60</sup>

Even if no feature of the model directly reflected disability, facially neutral features might still act as proxies, importing protected variables like race or disability into an algorithm’s predictions. One way this problem manifests is in “omitted variable bias”: when an important, influential variable—in this case, disability—is absent during the training stage. This absence, despite the variable’s outsized influence on the likelihood of the target outcome, can cause other variables to act as a sort of “algorithmic Trojan Horse,” importing the effect of the missing variable into the tool’s output while obscuring its role.<sup>61</sup> It is possible that this may be occurring with disability in these models as “other features in the model (like features related to eligibility for public benefits programs, involvement with the criminal legal system, or others)” act as “proxies for disability status.”<sup>62</sup>

Making matters worse, automated tools like the AFST may provide workers with little discretion to contest or override a risk flag or score. Doing so may require the approval of supervisors, most of whom do not interact directly with the family and thus rely on caseworkers’ judgment and available system data.<sup>63</sup> Even those with discretion to do so might be reticent to second guess the automated decisions and risk scores the tools presented to them.<sup>64</sup> After the AFST was deployed, for example, researcher Virginia Eubanks reported that even experienced call center workers asked to change their own previously-entered risk assessments in order to conform to tool-generated scores they later received.<sup>65</sup> Allegheny County Intake Manager Jessie Schemm explained the trust workers placed in the algorithmically-generated score: “If you get a report and you do

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<sup>60</sup> *Id.* at 1299. The Douglas County Decision Aid, being used in Douglas County, Colorado, similarly incorporates 218 “features” related to families’ use of public benefits, which may have similar effects. See VAITHIANATHAN, *supra* note 55, at 15.

<sup>61</sup> Stephanie K. Glaberson, *Coding Over the Cracks: Predictive Analytics and Child Protection*, 46 *Fordham Urb. L.J.* 307, 346-47 (2019).

<sup>62</sup> Gerchick, et al., *The Devil is in the Details*, *supra* note 58, at 1299.

<sup>63</sup> *E.g.*, Eubanks, *AUTOMATING INEQUALITY*, *supra* note 11 at 142.

<sup>64</sup> *See generally*, Danielle K. Citron, *Technological Due Process*, 85 *Wash. U. L. Rev.* 1249, 1271-72 (2008).

<sup>65</sup> Eubanks, *AUTOMATING INEQUALITY*, *supra* note 11 at 142.

all the research, and then you run the score and your research doesn't match the score, typically, there's something you're missing. You have to back-piece the puzzle.”<sup>66</sup>

AFST developers continue working with additional jurisdictions around the country to create additional, similar tools.<sup>67</sup>

## **2. Los Angeles' Risk Stratification Model**

The Risk Stratification Model (RSM) being piloted by the Los Angeles County Department of Children & Family Services (DCFS) is an automated tool used to help manage investigations and assess future risk of harm. Although the researchers behind the tool say that it is not used to direct case opening or removals, they also state that the tool helps with “ensuring supervisors and managers are not only responding to immediate safety concerns, but also proactively addressing conditions that may lead to future system involvement.”<sup>68</sup>

Like the AFST, the RSM draws from hundreds of records from databases to create a risk score for families.<sup>69</sup> According to the developers who also worked on the AFST, the RSM was created to be used in conjunction with other tools, and primarily aims to identify “already-open investigations recommended for enhanced supports in situations where history indicates a family’s service needs are likely more significant” and “investigations that may not have immediate safety concerns, but are at risk of future system involvement.”<sup>70</sup> Data used for the RSM includes information regarding a parent or child’s developmental disabilities, records of special education, prior mental health referrals, psychotropic medication use, indication of a missing toxicology report at birth, indication of prenatal substance exposure, developmental service or mental health needs, indication of possible homelessness, prior system history, as well as referral information like day and time of reports (summer holiday or winter holiday being flagged for risk).<sup>71</sup> These variables, amongst others, are used to generate a risk score

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<sup>66</sup> *Id.* at 141.

<sup>67</sup> *See, e.g.,* VAITHIANATHAN, *supra* note 55; Samant et al., *supra* note 56.

<sup>68</sup> *See* THE LOS ANGELES COUNTY RISK STRATIFICATION PILOT: AN OVERVIEW AND ONE YEAR UPDATE 15 (2022), [https://dcfs.lacounty.gov/wp-content/uploads/2022/08/Risk-Stratification-One-Year-Update\\_8.24.22.pdf](https://dcfs.lacounty.gov/wp-content/uploads/2022/08/Risk-Stratification-One-Year-Update_8.24.22.pdf).

<sup>69</sup> *See id.* at 3.

<sup>70</sup> *Id.* at 16, 68.

<sup>71</sup> *See id.* at 19, 23.

which indicates an investigation's risk for “future system involvement.”<sup>72</sup> Along with the algorithm, developers also piloted an “investigation overview report.” This report incorporates some of the variables used by the RSM to flag future risk and provides an overview of all allegations, cases, and placements related to the referral.<sup>73</sup> It also includes a separate section labeled “Indicators of Risk,” which lists a number of corresponding risk flags for the current referral such as “child w/ mental health svc referral” or “adult w/ maltreatment as a minor.”<sup>74</sup> Caseworkers and supervisors use information gleaned from this report to assist in their decision to substantiate a referral for child maltreatment.

### 3. Structured Decision-Making

Another example of a tool being used by multiple agencies to support screening, investigation, and other decisions is Structured Decision Making (SDM). SDM has been used in different jurisdictions including California, Florida, and Texas.<sup>75</sup> The SDM is split into six different assessments based on various system decision-making points, including hotline screening, safety assessment, risk assessment, and strengths and needs for reunification decisions.<sup>76</sup> The SDM Hotline tool is used to assess whether a referral meets the statutory threshold for “an in-person response.”<sup>77</sup> Through a web portal, workers are led through various prompts to mark whether or not a family meets certain criteria for neglect or abuse. If a worker marks one or more criteria as “yes,” the referral is flagged for in-person investigation. Numerous SDM criteria relate to health,

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<sup>72</sup> See *id* at 16.

<sup>73</sup> *Id.* at 18.

<sup>74</sup> *Id.*

<sup>75</sup> See *Structured Decision Making*, CALIFORNIA DEPARTMENT OF SOCIAL SERVICES, <https://www.cdss.ca.gov/inforesources/child-welfare-protection/structured-decision-making>; NATIONAL COUNCIL ON CRIME AND DELINQUENCY CHILDREN’S RESEARCH CENTER, *SDM® RISK ASSESSMENT CASE READING* (2019), <https://www.myflfamilies.com/sites/default/files/2023-05/FloridaCaseReadingReportJune2019.pdf>; NCCD, *Texas Department of Family and Protective Services Rolls Out New Risk Assessment for Child Protection*, EVIDENT CHANGE (2015), <https://evidentchange.org/newsroom/news-of-interest/texas-department-of-family-and-protective-services-rolls-out-new-risk-assessment-for-child-prot/>.

<sup>76</sup> See *California SDM Policy and Procedures*, EVIDENT CHANGE, <https://ca.sdmdata.org/Definitions/HT/PP#:~:text=The%20purpose%20of%20the%20hotline,and%20the%20path%20of%20response.>

<sup>77</sup> *California SDM Definitions*, EVIDENT CHANGE, <https://ca.sdmdata.org/Definitions/HT>.

mental health, or disability and may facilitate discrimination based on disability, including, for example:

- “Inadequate supervision: . . . Caregiver is unable to care for child due to substance use, mental illness, or developmental disability.”
- Threat of neglect defined as circumstances where “No event has occurred; however, conditions exist that create a substantial likelihood that the child will be neglected” including instances in which:
  - “Caregiver has not demonstrated capacity to meet child’s basic needs without external supports and external supports are no longer present.”
- Other high-risk birth (in-home only) defined as “No acts or omissions constituting neglect have yet occurred; however, conditions are present that suggest that the only reasons neglect has not occurred are the external supports of the hospitalization or the limited time since birth. Examples include but are not limited to the following:
  - . . . A mother of any age with apparent physical, emotional, or cognitive limitations has no support system and may be unable or unwilling to meet the newborn's basic needs.”<sup>78</sup>

Additional SDM tools that are used later in the case process include other disability-related criteria. For example, the SDM Safety Assessment tool is used to flag immediate safety concerns and to direct case opening or removal decisions. It includes criteria such as:

- Presence of “caregiver complicating behaviors” defined as “conditions that make it more difficult or complicated to create safety for a child but do not by themselves create a safety threat” which includes:
  - Substance abuse
  - Mental health (defined as “[o]ne or both caregivers appear to be mentally ill at the time of this incident or have a known history of mental health issues that have or could have impacted care of children”)

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<sup>78</sup> EVIDENT CHANGE. SDM POLICY AND PROCEDURES MANUAL 23-27 (2021), <https://ca.sdmdata.org/documents/CA%20SDM%20PP%20Manual.pdf>.



- Developmental/cognitive impairment (defined as “[o]ne or both caregivers may have diminished capacity as a result of developmental delays or cognitive issues that may impact their ability to provide care and supervision of children”)
- Physical condition (defined as “[o]ne or both caregivers has a physical condition that impacts care and protection of the child in the household.”)
- Significant diagnosed medical or mental disorder (defined as “[a]ny child in the household has a diagnosed medical or mental disorder that significantly impairs ability to protect him/herself from harm, OR diagnosis may not yet be confirmed but preliminary indications are present and testing/evaluation is in process. Examples may include but are not limited to: severe asthma, severe depression, medically fragile (e.g., requires assistive devices to sustain life), etc.”)
- Significant diminished developmental or cognitive capacity (defined as “[a]ny child in the household has diminished developmental/cognitive capacity, which impacts ability to communicate verbally or to care for and protect self from harm.”)<sup>79</sup>

Although the SDM has been described as helping “CPS workers employ objective assessment procedures at major case decision points,”<sup>80</sup> the above-described criteria are far from objective.<sup>81</sup> To the contrary, they risk serving as entry points for disability discrimination.

Michael Nash, head of the Los Angeles Office of Child Protection, previously highlighted the limits of the SDM from the perspective of workers. He shared:

*“Users of the tool, in particular, fault it for not incorporating into its assessments the entire story of what is happening within a family, but instead focusing on a few broad strokes without giving weight to important nuances. Users additionally state that the tool*

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<sup>79</sup> *Id.* at 50-61, 77.

<sup>80</sup> *Structured Decision Making (SDM)*, THE CALIFORNIA EVIDENCE-BASED CLEARINGHOUSE FOR CHILD WELFARE, <https://www.cebc4cw.org/program/structured-decision-making/>.

<sup>81</sup> Victoria A. Copeland, *It’s the Only System We’ve Got: Exploring Emergency Response Decision-Making in Child Welfare*, 11 Colum. J. Race & L. 43, 71-72 (2021).

*is too narrowly focused on the caregiver and does not take into account the strengths of the family as a whole.*<sup>82</sup>

Despite claims that safety and risk assessment tools are beneficial for system efficiency and provide “a scientific check” for human bias, the inclusion of health and disability related data into these tools may create or exacerbate assumptions about a parent’s capacity to provide adequate care based on their disability.<sup>83</sup>

Disabled parents’ increased vulnerability to reporting can also work as a feedback loop: even where reports are ultimately deemed unfounded, their existence remains documented in the data and may work to increase their future scores, marking families for further surveillance and investigation.<sup>84</sup> One caseworker shared that these referrals are extremely difficult for families to fight:

*“I had another family and there was, had to literally been 20 referrals made on the family even they though they weren't legitimate. There was all these different random ones, but every single one was documented. And I remember the mom was a little bit more savvy, and she was actually trying to use the law and had a lawyer to try to get them removed, and she still couldn't, like basically it didn't matter like that was gonna forever follow her. So basically when her little girl grows up if she ever was to become interacted with the system, they are now going to pull up the 20 reports that were on her when she was a kid. And so it just it was crazy to me that I was like y'all are watching and documenting everything and basically keeping a database of every misstep that you believe.”<sup>85</sup>*

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<sup>82</sup> Judge Michael Nash (Ret.), Examination of Using Structured Decision Making and Predictive Analytics in Assessing Safety and Risk in Child Welfare (May 4, 2017), [https://file.lacounty.gov/SDSInter/bos/bc/1023048\\_05.04.17OCPReportonRiskAssessmentTools\\_SDMandPredictiveAnalytics.pdf#search=%22OCP%22](https://file.lacounty.gov/SDSInter/bos/bc/1023048_05.04.17OCPReportonRiskAssessmentTools_SDMandPredictiveAnalytics.pdf#search=%22OCP%22).

<sup>83</sup> Sally Ho & Garance Burke, *Child welfare algorithm faces Justice Department scrutiny*, Associated Press (Jan. 31, 2023), <https://apnews.com/article/justice-scrutinizes-pittsburgh-child-welfare-ai-tool-4f61f45bfc3245fd2556e886c2da988b>.

<sup>84</sup> It must be noted that the data feeding these tools also is only collected on a subset of people: those interacting with government agencies such as public benefits systems, public hospitals, “preventive services,” and the criminal legal system. This results in disabled, black, latine, and low income individuals experiencing generational cycles of system involvement, surveillance, tracking and monitoring through data systems. See, e.g., Abdurahman, *supra* note 10, at 96 (“the prevented populations’ are people enrolled into community surveillance programs and a site of discipline by the therapeutic state”).

<sup>85</sup> Copeland, *supra* note 12.

Impacted community members have voiced their concerns with the use of these data driven tools. The Los Angeles County Community Child Welfare Coalition, a group of nonprofits and grassroots organizations, shared that “[p]redictive analytics could be used to create maps and information used to further marginalize certain populations or justify disproportionality in the Child Welfare system, based on race and bias.”<sup>86</sup> Further, family members in the Skid Row community of Los Angeles shared that they must remain aware of how they interact with the system, as judgements about their behavior and general affect are placed into computers.<sup>87</sup> A mother in Skid Row shared that these judgements can subsequently impact the way a caseworker treats them:

*“They do it the way they want to, long as they type the stuff in the computer and that's what they know about you, if you come in there a certain day, you say certain words, they type it. If you're aggressive that day they type it. And they not gonna say the day you came in nice, the aggressive part is going to be all over, and that's the way they're gonna treat you.”*<sup>88</sup>

Additionally, mothers in Skid Row shared that their interactions with the system including data collected from and on them “haunt[] you for the rest of your life.”<sup>89</sup> They discussed how constant surveillance impacted their mental and physical health, causing persistent stress and anxiety.<sup>90</sup> In one case, a mother experienced several miscarriages which she associated with the severe stress of being constantly monitored by the system with no hope of reuniting with her child.<sup>91</sup> Another was placed on an involuntary psychiatric hospitalization for fourteen days after her child was abruptly removed from her home.<sup>92</sup>

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<sup>86</sup> Daniel Heimpel, *Uncharted Waters: Data Analytics and Child Protection in Los Angeles*, The Imprint News (July 20, 2015), <https://imprintnews.org/featured/uncharted-waters-data-analytics-and-child-protection-in-los-angeles/10867>.

<sup>87</sup> Copeland, *supra* note 12.

<sup>88</sup> *Id.*

<sup>89</sup> *Id.*

<sup>90</sup> *See id.*

<sup>91</sup> *See id.*

<sup>92</sup> Victoria Copeland, *Dismantling the Carceral Ecosystem: Investigating the Role of “Child Protection” and Family Policing in Los Angeles*, 124 (2022), (Ph.D. Dissertation, University of California, Los Angeles) (ProQuest), <https://escholarship.org/uc/item/3rc7z257>. Under § 5150 of California’s Welfare and Institutions Code, a police officer or mental health professional who determines a person to be a danger

HHS should make clear that screening a report in for investigation, “substantiating” or “indicating” a report on the basis of assumptions about a parent’s disability, including through reliance on tools that incorporate disability data or have a disparate impact on individuals with disabilities, all violate federal law.

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In sum, Section 504 is intended to protect individuals with disabilities and their families from discrimination. As written, the proposed rule fails to reach the sites in the system where that discrimination is most likely to occur, and which stands to affect the largest number of families.

## **II. RECOMMENDATIONS**

HHS should ensure that the proposed rule works to interrupt discrimination at the front end of the system, where most families encounter it, and where protections can make the most difference. HHS can do so by:

1. Clarifying that the definition of “child welfare program or activity that receives Federal financial assistance” in § 84.60(a)(1) includes reporters such as education, medical, mental health, social services, law enforcement, and other professionals who are part of programs that receive federal financial assistance.
2. Including in § 84.60(b) prohibitions on the following activities in addition to those already listed:
  - a. Making a report of suspected child maltreatment on the basis of speculation, stereotypes, or generalizations about a parent’s disability
  - b. Screening in for investigation, substantiating or indicating a report of suspected child maltreatment on the basis of speculation, stereotypes, or generalizations about a parent’s disability, including through the use of disability data and data-driven tools.

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to others or themselves due to a mental health condition can involuntarily detain that person for up to 72 hours. Under § 5250, this “5150 hold” can be extended to 14 days (“a 5120 hold”).

### III. CONCLUSION

We thank the Department for its attention to this important issue. For the reasons stated here, we urge the Department to revisit its proposed rule and expand its scope to include the front end of the system, where the highest number of families stand to benefit from increased protections against disability discrimination.

Respectfully submitted,

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