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## **Lived Experience and Disability Justice in the Family Regulation System**

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## LIVED EXPERIENCE AND DISABILITY JUSTICE IN THE FAMILY REGULATION SYSTEM

L. Frunel & Sarah H. Lorr\*

*“ACS labeled me dirty as if cleaning me up. I am not dirty,  
I am not a disease, I am not a body, I didn’t come in here  
empty-handed.”*

– L. Frunel

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\* L. Frunel is a parent and activist who is currently fighting for her family in the child welfare system. Ultimately, because of fear of jeopardizing her legal case, she has chosen to publish this piece under an assumed name. Sarah H. Lorr is an Assistant Professor and Co-Director of the Disability and Civil Rights Clinic at Brooklyn Law School. She gratefully acknowledges the network of advocates who supported her in this project: Joyce McMillan, Prianka Nair, Tarek Ismail, Julia Hernandez, and Amy Mulzer.

## I. INTRODUCTION

The public family regulation system is predicated upon laws and policies which are purported to value family reunification as the primary goal.<sup>1</sup> These laws and policies are in turn built on the premise of equitable treatment of the parents and families who become involved in the system.<sup>2</sup> And yet, the system fails to live up to these standards. Parents who may need, and in turn seek, legitimate support from the state are seen as frail, incapable, and broken. Parents who do not seek to remedy supposed “flaws” in their approach to parenting are viewed as resistant, noncompliant, and unworthy of parenthood.

Parents identified as having a disability face additional challenges. System stakeholders—from case planners to lawyers to judges—readily pathologize parents with disabilities, largely ignoring their voices and experiences, despite their intimate knowledge of their own and their children’s needs. Disability or diagnosis itself can be seen as synonymous with the inability to parent. Given the pervasive bias against parents with disabilities, the family regulation system’s supposed goal of equitable treatment remains an unrealized promise; parents with disabilities face much higher rates of separation and lower odds of reunification than parents without disabilities.<sup>3</sup>

In the family regulation system, the label of disability specifically impacts how parents are treated, including whether they are offered meaningful support and an equal opportunity to be reunited with their children. Indeed, the label of disability is used to strip parents of rights and credibility. Caseworkers, judges, and attorneys often fail to understand the nature of disability while simultaneously espousing and adopting harmful stereotypes of disability to conclude that disabled parents cannot parent.

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<sup>1</sup> See *Matter of Lacey L. (Stephanie L.)*, 32 N.Y.3d 219, 223 (2018) (“The primary goal of New York’s child welfare scheme is safe family reunification.”); Adoption Assistance and Child Welfare Act of 1980, 42 U.S.C. § 622 (2018) (requiring states to make reasonable efforts to prevent removal and, once children are placed into foster care, to make reasonable efforts towards family reunification); N.Y. SOC. SERV. LAW §§ 384-b (1)(a)(ii), (iii) (demonstrating it has long been the public policy to keep biological families together and to require foster care agencies to exercise diligent efforts to reunite abused and neglected children with their birth parents, once rehabilitated; see also CHILD. BUREAU, DEP’T OF HEALTH & HUM. SERVS., REASONABLE EFFORTS TO PRESERVE OR REUNIFY FAMILIES AND ACHIEVE PERMANENCY FOR CHILDREN: STATE STATUTES 1–2 (2016), <https://www.childwelfare.gov/pubPDFs/reunify.pdf> [<https://perma.cc/WNJ5-V8C9>].

<sup>2</sup> Shortly after parents and advocates filed a class-action lawsuit against New York City for violating the rights of parents who have intellectual disabilities, Commissioner of the Administration of Children’s Services David Hansell issued a statement in which he asserts that “[t]reating all parents equitably is vital in our work.” Nikita Stewart, *Disabled Parents Sue New York City Over Child Removals*, N.Y. TIMES (Oct. 9, 2017), <https://www.nytimes.com/2017/10/09/nyregion/parents-with-intellectual-disabilities-sue-new-york-city.html> [<https://perma.cc/645Y-54LSJ>].

<sup>3</sup> Parents with an intellectual disability are more than three times as likely to have their parental rights terminated than parents without a disability, and their children are removed at rates as much as eighty percent higher than are children of non-disabled parents. NAT’L COUNCIL ON DISABILITY, ROCKING THE CRADLE: ENSURING THE RIGHTS OF PARENTS WITH DISABILITIES AND THEIR CHILDREN 16 (2015) [hereinafter ROCKING THE CRADLE], [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) [<https://perma.cc/DSB6-KVUY>]. Parents with psychiatric disability face child removal rates that are seventy to eighty percent higher than parents without a disability. *Id.*

Parents who resist diagnosis with a disability are likely to be denigrated as unable to understand themselves and their children by reason of disability. Those who embrace or acknowledge their disabilities can be penalized for exhibiting behaviors relating to their disabilities or even for seeking help.

This Piece explores how ableism operates in the family regulation system to create the ongoing pathology of parents with disabilities and of parents who have been labeled as disabled by the system.<sup>4</sup> Specifically, we share one co-author's inequitable experiences of being pathologized. By presenting the lived experience of one parent in the family regulation system who initially sought help from the system and was later labeled as having a psychiatric disability, we expose how,—regardless of a parent's disability status—their experience in family court is irrevocably marred once they are saddled with a disability label.

Our approach is guided by the Disability Justice framework. Disability Justice recognizes that “all bodies are unique and essential” and simultaneously that “all bodies are confined by ability, race, gender, sexuality, class, nation state, religion, and more, and we cannot separate them.”<sup>5</sup> A Disability Justice lens demands an inherently intersectional analysis recognizing that “we are many things, and they all impact us.”<sup>6</sup> Accordingly, it demands not only that we “gratefully embrace the nuance . . . [of] our lived experiences,” but that we understand the way these intersectional identities shape both how we perceive and how we are perceived.<sup>7</sup>

The Disability Justice framework guides us to a potential way forward in the family regulation context. Just as Disability Justice as a movement calls for “leadership of the most impacted,” the authors of this Piece believe that impacted communities have the capacity to strengthen themselves and the families that exist within them, and that parents and families themselves know what it is they most need.<sup>8</sup> Any system truly

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<sup>4</sup> We adopt the definition of ableism offered by Liat Ben-Moshe: “Ableism is oppression faced due to disability/impairment (perceived or lived), which not only signals disability as a form of difference but constructs it as inferior.” LIAT BEN-MOSHE, *DECARCERATING DISABILITY: DEINSTITUTIONALIZATION AND PRISON ABOLITION* 16 (2020) [hereinafter BEN-MOSHE, *DECARCERATING DISABILITY*]. We also draw on Ben-Moshe's offered definition of sanism as “oppression faced due to the imperative to be sane, rational, and non-mad/crazy/mentally ill/psychiatrically disabled.” *Id.* at 16–17 (citing Michael L. Perlin, *On Sanism*, 46 S.M.U. L. REV. 373 (1993)).

<sup>5</sup> SINS INVALID, SKIN, TOOTH, AND BONE: THE BASIS OF MOVEMENT IS OUR PEOPLE: A DISABILITY JUSTICE PRIMER 19 (2d. ed. 2019) [hereinafter DISABILITY JUSTICE PRIMER].

<sup>6</sup> *Id.* at 23.

<sup>7</sup> *Id.* This is connected to Lennard J. Davis's idea of the “dismodern” body, which begins from the premise that we are all disabled and need assistance and interdependence in order to survive—ranging from legislation to technology. LENNARD J. DAVIS, *BENDING OVER BACKWARDS: DISABILITY, DISMODERNISM AND OTHER DIFFICULT POSITIONS* 30 (2002). Under this premise, it is not unnecessary or unusual to require assistance or support from the state, and notions like independence are exposed as being artificial. *Id.*

<sup>8</sup> “When we talk about ableism, racism, sexism & transmisogyny, colonization, police violence, etc., we are not looking to academics and experts to tell us what's what—we are lifting up, listening to, reading, following, and highlighting the perspectives of those who are most impacted by the systems we fight against.” DISABILITY JUSTICE PRIMER, *supra* note 5, at 23. Ben-Moshe, like many other scholars and activists in this field, also acknowledges the value of centering the experience of the most disabled in shaping law and policy. *See*

concerned with the welfare of children must recognize the inherent wholeness of all families—and the people who make them up—and allow families and parents themselves to design and seek the supports that they require.

This is in stark contrast to the system as it currently functions, where caseworkers, lawyers, judges and others outside of the family unit—who also systemically operate from outside of the family’s community or culture—dictate what supports or services are supposedly necessary or beneficial for the parent and family.<sup>9</sup> In practice, the “services” are likely to be selected from a menu of pre-existing programs offered by providers with whom the state or city has a contract. In essence, parents are forced to participate in time-consuming programs meant to “support” them and improve their parenting skills, based on the vision of caseworkers or judges who do not know or understand the material needs of the parent and family. Parents who accept the offered services often have their true needs go entirely unaddressed. Parents who do not engage in the required services are pathologized for rejecting them, even if they are unnecessary or inappropriate. This double bind, along with the coercion and bias embedded in the system, leads us to conclude that the current system is untenable.

In Part I, L. Frunel, a mother whose children are currently in foster care, shares her experience of having her children removed and then placed out-of-state after she was labeled with a disability, despite her completion of each “service” the New York Administration for Children’s Services (“ACS”) has asked her to undertake.<sup>10</sup> The state removed her children nearly two years ago. As of this writing, Ms. Frunel still has not had a trial and she continues to fight for her family to be reunified. Due in part to the ongoing COVID-19 pandemic and the placement of her children in another state, she has not had an in-person visit with them in more than one year. What began as a case of alleged corporal punishment morphed into the ongoing surveillance and pathology of Ms. Frunel, intensified in part by a merely suspected mental health diagnosis. She uses the first-person singular as she presents her narrative in Part I and as she elaborates on her experience throughout the Piece.<sup>11</sup>

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*generally* BEN-MOSHE, *supra* note 4 (consistently “center[ing] activist movements anchored by those most affected” throughout analyses of carceral policies and institutions).

<sup>9</sup> In the current system, so-called services and supports can consist of required participation in anything from parenting or anger management classes, to therapy, to domestic violence counseling, and other programs. See *Parent’s Guide to Foster Care*, NYC ADMIN. FOR CHILD. SERVS., <https://www1.nyc.gov/site/acs/child-welfare/parents-guide-to-foster-care.page> [https://perma.cc/ST7U-UT89] (“[T]he agency case planner will work with you and your family to develop a comprehensive assessment and a service plan which will include . . . services such as counseling and medical evaluations depending on the . . . circumstances of your case.”).

<sup>10</sup> The authors seek to emphasize that the story of Ms. Frunel’s experience is neither representative of the experiences of all system-involved parents, nor is it meant to essentialize experiences of parents labeled as having a disability. Instead, it is our hope that the experiences relayed here will shed light on some of the experiences of others in the system and impart valuable learnings about the family regulation system.

<sup>11</sup> In addition to using the first person singular, we use italics to delineate sections that derive solely from Ms. Frunel’s experiences.

In Part II, we discuss how ableism operates as a force within the system, using examples from Ms. Frunel's experience to illustrate related systemic problems. Specifically, we explore how Ms. Frunel's experiences expose the system's biased and superficial ableist understandings, the system's reliance on a medical model of disability, and the system's failure to listen to and trust parents.

Part III calls for a reimagining of the family regulation system, naming specific avenues of "non-reformist" reform. We urge the adoption of a conception of "child welfare" anchored in the Disability Justice movement, which recognizes that "all bodies have strengths and needs that must be met."<sup>12</sup> Based on Ms. Frunel's experience with the overlapping family regulation and criminal justice systems, we seek a model that is non-adversarial and support-based. After briefly describing our hopes for the development of an alternative approach to supporting families, the authors put forth specific suggestions aimed at improving experiences and outcomes for families. These reforms, though far from the full reimagining we ultimately seek, are offered in recognition that the current adversarial and punitive system continues to actively harm families. We present these reforms as a path to minimize the ongoing damage caused by the system and, ultimately, as a means of shrinking the system itself.

## II. COMING UNDER THE FAMILY REGULATION SYSTEM

*In late 2018, I learned I was the subject of an anonymous complaint about child abuse when a caseworker came to my apartment door. I was in my forties; I had never had any interaction with foster care or the court system. Both my children were honor roll students, and both were involved in a number of activities: swimming, basketball, the choir at church, and the children's ministry.*

*My son is on the Autism spectrum. He has Attention-Deficient/Hyperactivity Disorder ("ADHD") and sensory processing challenges. He has an Individualized Education Program ("IEP"),<sup>13</sup> and I have devoted significant parts of my professional life to making sure he is learning and being given real support. I took a five-year professional sabbatical because he was detected to have reading challenges. During that time, I would stay with him after school and teach him. I first had to teach myself the phonetic instructions and then teach him. This is the family that ACS met in 2018.*

*Without knowing anything about ACS, I welcomed the caseworker into my home. She wanted to speak to me and my children, and I let her; I was naïve and blindsided. She asked questions, looked for food, and looked*

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<sup>12</sup> DISABILITY JUSTICE PRIMER, *supra* note 5, at 19.

<sup>13</sup> Federal law, particularly the Individuals with Disabilities Education Act ("IDEA"), provides for students with disabilities to receive free and public education services through Individualized Education Programs formulated by parents and school officials to meet the students' needs. 20 U.S.C. § 1412(a)(1); *Andrew F. v. Douglas Cnty. Sch. Dist.* RE-1, 137 S. Ct. 988 (2017) (interpreting the substantive obligations of the "individualized education program" under IDEA). *Cf.* Cynthia Godsoe, *Caught Between Two Systems: How Exceptional Children in Out-of-Home Care are Denied Equality in Education*, 19 YALE L. & POLY REV. 81, 91–94 (2000) (detailing the IEP, in the context of an examination of child welfare at the intersection of the family regulation system and exceptional children's educational access).

at my children's bodies. She said she didn't see any indication of abuse or neglect.

*At the time, I was going through a bitter divorce, so I asked for services. I explained that my husband had moved out of state, that I was the primary parent, and that there had been domestic violence. I explained that my son was on the Autism spectrum. I was managing all of this on my own and I wanted help. She said no and explained that the report would close in sixty days.*

*A few months later, in early 2019, I received a call from ACS saying that they were going directly to my son's school. My children were seven and nine years old. My mom—who used to help me watch the kids while I worked—went to the school while ACS was there. They all went to the police station, where my son was interviewed by a police officer. The officer told my mother she could not go inside; my son was alone. When I arrived at the station, the police officer told me that their mom used to hit them too. The officer asked me what happened. I had never been arrested before, but I knew I had a right to a lawyer; I didn't answer any questions. I was then arrested and accused of hitting my son with a broom, a mop, a dustpan, and a toy sword.*

*In criminal court, I was charged with three different counts based only on my son's statements. I was assigned an attorney and told I would be facing a Class F felony. I was released on my own recognizance—meaning that I was allowed to leave without bail. I was in my forties and had no criminal history. With assistance from my family, I secured a private attorney, and the criminal charge was adjourned in contemplation of dismissal and eventually dismissed.*

*Once released, I was told to meet ACS at family court for a meeting. Again, I had never had any experience with family court; I had no idea this would be a court case or that I could be accused of doing something else wrong when I already had a criminal case that was dismissed. I arrived at the meeting and told them I didn't want to participate without an attorney. I had just left my attorney in criminal court. My attorney was clear that I shouldn't talk about the case. The caseworker from ACS told me, "You don't need an attorney, you are here just to do a family-based assessment." I didn't know what that meant or the risk that I was taking by speaking to them.*

*During this meeting, ACS asked about my mental health. The caseworker asked specifically if I was bipolar. I didn't see a negative stigma with having bipolar disorder. To me, it is better to identify if you have a health condition, to seek treatment and go to the doctor—get the proper medical attention for it. In my family, mental health conditions may be considered a taboo, but I had learned to empower myself when it comes to mental health and any mental health concerns. So, when they said the word "bipolar," I said that I didn't know—"I could or I couldn't be. I don't have any symptoms of it, but I need to be aware of these things so that I can teach my children these signs, so that they are conscious of their stress and their environments and what could take them to overload." I felt at the time like I was in a safe place where I could be vulnerable. I used that as a moment to talk about recognizing bipolar disorder in a good way, not knowing that it would be used as a weapon against me.*

*The next day, ACS raised my mental health in court. They told the judge what I had said—specifically, that I did not deny having bipolar disorder. From there, ACS subjected me to a series of health evaluations, trying to prove that I have bipolar disorder while assuming that I do. When ACS labeled me as bipolar, they also assumed I was violent, incompetent, unstable, and unable to take care of my children without the help of someone else. To them, the word “bipolar” meant that I, as the one with that label, was a violent individual so my children were not safe around me.*

*After the family court case was filed, I felt personally ambushed and attacked. Because I was charged with excessive corporate discipline, any mark on my child’s body was considered an abuse from me. It couldn’t simply be because he fell. And if I got angry, I was told that those emotions were not healthy. They would ask, “How can you be around your children?” ACS thinks, “I don’t like your behavior, the way you speak to me. I don’t like the way you parent.” I am an educated, working-class professional. This meant that ACS was intimidated by my ability to read, write, and converse at a higher level of articulation than the stereotype of most parents whom they interact with. So, they considered my questions and my responses to emails to be defiant behavior.*

*As a mother, I thought it was disrespectful that the judge would trust people around my children without providing copies of their qualifications or copies of their roles and responsibilities. I am a global project manager and I come with training and a professional skill set, so if I identify a goal, I am trained to follow up in communication with emails and to ask what we are trying to accomplish. I asked the judge, “If I hire a nanny, I have the ability to interview them, get their qualifications. Why is it that you are putting state workers with me and I don’t have access to any of their information?” Yet, they felt that I was being disrespectful.*

*There was a lot of intellectual questioning and unfair treatment. The judge said, “She is very articulate.” When I asked to represent myself, the judge asked me if I could read legal books. While the judge allowed ACS to dominate the courthouse, the judge silenced me. ACS created fights or, really, confrontation, to then profile me as a violent person. But that doesn’t hold up. If I was violent, I would be doing time in criminal court. Also, I am being tried twice for the same allegations. One system (the criminal system) dropped it, the other system (family court) picked it up and magnified it using their wild imagination.*

*I was discredited, my character was slandered. They’re committing human abortions. Taking someone’s family away is an abortion. And it is also my body, my choice. This is about reproductive rights. Being on medication doesn’t mean that you are fine, being off medication doesn’t mean you are fine. If I had a disability, I would have had all of these other accommodations in the past thirty years of my life. I haven’t had that. But, after my brief encounter, I now have all these supposed ailments because CPS said so, yet no accordant care or support. Unverified by doctors and, still, CPS has kept pushing these pathologies until we go to trial. It shouldn’t have to go this far, to the point that they are literally trying to break me down to say, “Oh we got you.” But if I am crazy—you made me this way.*



*ACS is trying to control my thoughts, actions, behavior, my walk—everything about me. They are really wanting to reinvent me to be a criminal, discreetly, so that they can take away my kids. And the more I rise and resist the status quo, the less I see my kids. Now I have no visits at all, and it feels they are secretly moving towards a termination of parental rights. The mind games, the mental hazing, the gaslighting, the emotional and verbal abuse . . . I had never experienced this before. My mom and dad would never speak to me this way. Why is it acceptable from this agency and nothing is done about it?*

*At this time in 2021, my children have been moved to another state where they are living with their father. I have not seen them in person—sat with them, played with them, done schoolwork with them—in more than a year. I have also not had a trial, and instead have been presumed guilty and separated from my children based on the words of ACS. ACS labeled me dirty as if cleaning me up. I am not dirty, I am not a disease, I am not a body, I didn't come in here empty-handed. You can't break a person who is already built. Because I came with a strong foundation.*

### III. ABLEIST AND PREJUDICIAL CONCEPTIONS OF DISABILITY IN A CARCERAL SYSTEM

Ms. Frunel's case illustrates multiple problems with the family regulation system as it relates to parents with disabilities and to parents labelled as having disabilities. First, Ms. Frunel's case exemplifies the extent to which system stakeholders maintain a biased and superficial understanding of disability that affirmatively harms parents and their families. Second, her case demonstrates various ways that the medical model of disability is entrenched in the system. Under the medical model, a hyper-focus on diagnosis can mean zeroing in on disability-related concerns and leaving other, more basic, concerns unaddressed. Third, Ms. Frunel's experience reveals that when caseworkers and other stakeholders fail to center parents and their needs, they can perpetuate a deep lack of trust. The failure to listen to parents can mean that courts and caseworkers disregard requests for specific services to the detriment of children and families.

#### A. Biased and Superficial Understandings of Disability

Caseworkers, lawyers, judges, and other actors within the family regulation system frequently have only a limited understanding of the needs of parents with disabilities and penalize parents who identify as having a disability.<sup>14</sup> As a result, parents seeking assistance or bearing a disability label often find themselves in an impossible situation. On one hand, if a child welfare investigator—typically someone who is not a doctor or mental health professional and who therefore lacks the qualifications to make a diagnosis of disability—imposes a label of disability based on their “concerns” or “observations,” and a parent resists services, that parent may

<sup>14</sup> See Robyn M. Powell & Sasha M. Albert, *Barriers and Facilitators to Compliance with the Americans with Disabilities Act by the Child Welfare System: Insights from Interviews with Disabled Parents, Child Welfare Workers, and Attorneys*, 32 STAN. L. & POL'Y REV. 119, 147–155 (2020); Traci LaLiberte, *Are We Prepared? Child Welfare Work with Parents with Intellectual and/or Developmental Disabilities*, 7 J. PUB. CHILD WELFARE 633, 636–37 (2013); ROCKING THE CRADLE, *supra* note 3, at 100.

be penalized and denied a voice in the parenting of their child. Indeed, parents who are identified as “flawed”—perhaps due to a prior diagnosis, an emotional reaction during the removal of a child, or the judgment of an unqualified caseworker—and do not seek to remedy or “fix” themselves, are labeled resistant, noncompliant, unstable, and/or uncooperative.

Alternatively, when parents are diagnosed with a disability, they are not provided with adequate supports or services, and they may even be penalized for exhibiting behaviors relating to that disability. For example, when a parent with an intellectual or learning disability fails to learn from the cookie cutter services offered to all parents, such as a parenting class that has not been adapted for a parent with a disability, the parent is not provided with an appropriately tailored service but far more often identified as “unteachable” or unable to learn and, ultimately, as unworthy of parenthood. Like Ms. Frunel, they are frequently penalized for seeking services.

Moreover, they are commonly not permitted to rely on the natural supports in their lives. Parents who may seek or need legitimate support—for example, those who rely on support staff to assist with grocery shopping or a family member for assistance with caretaking—are seen as frail, incapable, and broken. These parents, like Sara Gordon, a parent with an intellectual disability in Massachusetts whose discriminatory treatment was the subject of an investigation by the U.S. Department of Justice (“DOJ”), are often assumed to be incapable of parenting by virtue of their diagnosis alone. In Sara Gordon’s case, she was denied the opportunity to rely on her family and service providers and, instead, forced to parent independently.<sup>15</sup> After Ms. Gordon filed a complaint with the Office of Civil Rights at the DOJ, the DOJ determined that the Massachusetts family regulation investigators wrongfully assumed that Ms. Gordon was unable to learn how to safely care for her daughter because of her disability.<sup>16</sup> She was also inappropriately denied the opportunity to receive meaningful assistance from her mother and other service providers during visits.<sup>17</sup>

In the case of Ms. Frunel, her caseworker’s suspicion that she might have a mental health diagnosis fundamentally altered the nature of her case. Indeed, once her caseworker asked about a specific diagnosis and Ms. Frunel did not immediately deny it, the case morphed from the specific allegation that she had improperly disciplined her child, to a broader pathologizing condemnation of her mental health and general fitness to parent.

*When I first met with ACS and they asked about my mental health, I did not know that when you are stigmatized and manufactured as having a mental health disability, you are facing a civil death penalty because they are essentially trying to slowly remove your children indefinitely, whether*

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<sup>15</sup> Letter from Vanita Gupta, Acting Ass’t Att’y Gen., U.S. Dep’t of Just. Civil Rights Div., Jocelyn Samuels, Dir., U.S. Dep’t of Health & Hum. Servs. Off. for Civil Rights, et al., to Erin Deveney, Interim Comm’r, Mass. Dep’t of Child. & Fams. 2–3 (Jan. 29, 2015), [https://www.ada.gov/ma\\_docf\\_lof.pdf](https://www.ada.gov/ma_docf_lof.pdf) [<https://perma.cc/8SHR-GN5M>] (reporting the DOJ’s conclusions from its investigation).

<sup>16</sup> *Id.*

<sup>17</sup> *Id.*

*you are on medication or not on medication. It is the most painful and awful treatment because there is no statute of limitations or due process, and they are not factoring in criminal case outcomes. Though I was charged with using excessive corporate discipline in the criminal case that was dismissed, I was labeled as having a mental illness when we got to family court. Nothing about my mental health was in the petition, but ACS was arguing that because I was bipolar and not being treated, I had abused my child.*

*My choice to be honest—to admit that I didn't know whether I would or would not have a mental health diagnosis—turned into a series of mental health evaluations. Seven different evaluations so far. They said to go get a mental health evaluation but didn't make a referral or tell me where I should go. So, first, I went to a therapist. She did not say that I had bipolar disorder; she said it was stress and anxiety. Then ACS said it had to be a medical doctor. I went to the doctor and shared the result, but then ACS said they wanted to be included in the evaluation. My doctor said they don't need to be included, and explained that evaluations are done directly with individuals, by themselves, and not with ACS involved. That doctor had seen me in the past, for postpartum depression. ACS specifically asked her if she thought I was bipolar. At first, she said she didn't know, but ACS wanted to know: Is she bipolar or not? So, she changed her letter to ACS to say that I "may or may not be" bipolar. I learned from the medical receptionist that ACS was trying to commit the doctor to the diagnosis so much that eventually she stopped taking calls from ACS.*

*ACS even tampered with my evaluation. One of the social workers at ACS said, "According to the medical records, you need medication." I said, "It doesn't say that in any of my evaluations—where do you see that?" She said, "Why do you think you are here, then?" That's when attacks became about punishing me, not helping me. The social worker was punishing me for allegations of neglect.*

*My third evaluation was from a Black therapist. I was doing talk therapy with her. I wanted to see a culturally sensitive and culturally appropriate therapist who I connected with. I liked this therapist. My lawyer at the time told me I should see a white therapist. She said ACS would like that more. I said, "Absolutely not." Yet my lawyer continued to insist that it was what ACS would like to see.*

*At this point, the judge threw out the mental health evaluation from the medical doctor because ACS was trying to coerce a diagnosis. So, I had to do another one. My fourth evaluation was at a hospital that another lawyer referred me to. They told me that I don't need inpatient treatment or medication, but also said that "if you do need medication, we have someone who can help you with a medication plan." I paid for these services on my own and was not reimbursed or otherwise compensated by the system.*

*I had done all of these evaluations and completed my service plan within four months: parenting, anger management, and individual therapy all done in four months. I had done everything except take medication. I wanted to know, "When are we going to move from supervised visits to unsupervised?" ACS said it would be indefinite. Because I was not taking medication, I had an unlimited period of only supervised visits.*

## B. Reliance on the Medical Model of Disability

Ms. Frunel's experience makes vivid the focus on diagnosis and medication that governs the lives of people labeled as having a disability in the family regulation system. Indeed, the medical model of disability—long understood by advocates to erode personhood—is pervasive in the family regulation system. The medical model understands and explains disability according to whether a person carries a specific diagnosis or an “individual medical problem.”<sup>18</sup> In contrast, the social model recognizes that disability is a social construction which exists within—and often because of—norms defined by broader society.<sup>19</sup> Importantly, “[i]n addition to pointing to the tangible environmental and structural changes that could be made to be more inclusive for people of differing body types, the social model of disability focuses attention on the attitudinal obstacles faced by people with non-standard bodies.”<sup>20</sup> In applying the social model beyond the physical body, Jamelia Morgan has observed that the “social model locates the meaning and import of . . . differences, and perceived limitations, in societal barriers, attitudes, and responses to disability, and not solely in the individual's biological attributes.”<sup>21</sup>

The medicalization of disability fits neatly with the view that disability is an individual pathology and encourages focus on personal failures rather than examination of conditions created by broader society. In Ms. Frunel's case, the emphasis on her theoretical disability prompted ACS to begin a long hunt for a diagnosis with a heavy emphasis on medication. This focus came at the expense of other aspects of her life and her relationship to her children. ACS, her lawyers, and the court have entirely overlooked the realities of her life that were likely causes of distress or overwhelm, and that they ostensibly could have assisted with, such as: her ongoing divorce; her transition to single parenthood as a working mother; her history of domestic violence at the hands of her former partner; her extensive efforts to find her son appropriate educational services; and, perhaps most chillingly, her encounter with the system itself. In Ms. Frunel's words:

*After four months in the system, I felt beaten into submission. I have talked with other parents who became suicidal and depressed, and who wanted to fight. I met these parents at a program for mothers. The program was still part of the system but allegedly there to help parents. When I think about that program, I think it is unfortunate that it was a service that was only provided after allegations were made, rather than one that was available to me before ACS came into my life. Services should have been provided to the community and at the schools beforehand, and ACS should*

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<sup>18</sup> Elizabeth F. Emens, *Framing Disability*, 2012 U. ILL. L. REV. 1383, 1401 (2013); see also Jamelia Morgan, *Policing Under Disability Law*, 73 STAN. L. REV. 1401, 1406 (2021) (offering a clear definition of the medical model and citing various other definitions).

<sup>19</sup> Morgan, *supra* note 18, at 1402.

<sup>20</sup> Sara Goering, *Rethinking Disability: The Social Model of Disability and Chronic Disease*, 8 CURRENT. REVS. MUSCULOSKELETAL MED. 134, 135 (2015).

<sup>21</sup> Morgan, *supra* note 18, at 1407–08 (“Treating disability as a social construction helps to emphasize its relational, contingent, fluid, and subjective nature.”) (citing Miranda Oshige McGowan, *Reconsidering the Americans with Disabilities Act*, 35 GA. L. REV. 27, 90–91 (2000)).

*be held accountable for not providing them in December when they first came to my home.*

*Prior to coming into this case, I was spirited to conquer the world. Now, I feel broken. I have anxiety attacks, Post-Traumatic Stress Disorder, nightmares, and things of that nature. What I didn't have before, I am starting to feel now. It makes me second guess whether or not I should discuss my mental health with someone, particularly whether or not it can be weaponized against me. It makes me afraid to talk about it. When you go to a doctor, they are quick to put you on medication. And once you get labeled with bipolar disorder, it never goes away. The label remains the same, no matter what changes.*

*What I find interesting is that "bipolar" is a quick umbrella term that both relies on stigma and is commonly used to advance stigma, particularly the stigma of an angry Black woman who needs to be on medication because of two extreme personalities or mood swings. I don't have depression, I don't have anxiety, I am well aware of my environment, I eat well, and I have a great support team. Because I speak another language, and also in another dialect, I may speak a lot more rapidly and switch up my tone if I am angry, but that is not an indication that I should be labelled as "bipolar."*

### C. The System's Failure to Center Parents

The system's general refusal to listen to and trust parents to be active participants in their own lives contributes to the lack of trust that many parents feel about their caseworkers and the broader system.<sup>22</sup> It is also a missed opportunity to learn from parents about what it is they need. For parents with disabilities, the system's failure to seek insights from parents themselves compounds the problems of bias and the lack of disability-related expertise that pervade the system more generally.<sup>23</sup>

Ms. Frunel's case exemplifies the extent to which caseworkers fail to meaningfully engage with the very parents that the system professes to assist. Her caseworkers did not recognize Ms. Frunel's expertise related to the circumstances of her own life or to the kinds of support she might actually need. In her very first interaction with ACS, Ms. Frunel requested assistance and was denied. Instead, this initial investigation was closed.<sup>24</sup> When ACS returned to her life and accused her of engaging in corporal punishment, she once again sought assistance. This time, certain services

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<sup>22</sup> This dynamic may be due in part to the adversarial framework in which the system operates. Mandatory reporting, for example, "establishes an adversarial relationship between the State and the parent at the outset of the relationship." Vivek Sankaran, *Innovation Held Hostage: Has Federal Intervention Stifled Efforts to Reform the Child Welfare System?*, 41 U. MICH. J. L. REFORM 281, 285, 295 (2007). For further discussion of mistrust between parents and the state, see Erin Miles Cloud, *Toward the Abolition of the Foster System*, BARNARD CTR. FOR RSCH. ON WOMEN: SCHOLAR AND FEMINIST ONLINE (2019), [http://sfonline.barnard.edu/unraveling-criminalizing-webs-building-police-free-futures/toward-the-abolition-of-the-foster-system/#identifier\\_48\\_4262](http://sfonline.barnard.edu/unraveling-criminalizing-webs-building-police-free-futures/toward-the-abolition-of-the-foster-system/#identifier_48_4262) [<https://perma.cc/9VHD-WJCM>].

<sup>23</sup> For a discussion on the lack of training and expertise among family regulation investigators and case workers, see Robyn Powell et al., *Terminating the Parental Rights of Mothers with Disabilities: An Empirical Legal Analysis*, 85 MO. L. REV. 1069 (2020).

<sup>24</sup> See *infra* Part I (describing this initial investigation).

were offered but only after ACS sought the removal of her children in court and, again, without regard for Ms. Frunel's perspective on what kinds of support she needed.

*When I met with my caseworker in 2019—at the meeting where she told me I didn't need a lawyer—the caseworker told me, “We need to talk to you about strengths and weaknesses of services we could provide you.” And, of course, I was in need of services. I was so relieved when she talked about helping us. I thought, “Okay, great, finally I can get some help.” I was estranged from my husband, who had been violent with me. Of course, the divorce and the domestic violence had impacted not only me but also my children. At the same time, I had been trying to get Department of Education services for my son and counseling for all of us. I had been running around to different doctors and not getting any services, all as a newly single mother.*

*The caseworker led me to believe that parenting classes would help with special needs parenting and single parenting. She also said that whether or not I did anything wrong, they wanted to make sure that I was aware of different disciplinary tools. For this reason, they asked me to take anger management classes.*

*The meeting ended with her telling me that, just to make sure that there is no further tension, ACS was asking that the children stay with my parents. I was comfortable with this, especially since they already stayed there when I went to work. She told me that I just needed to do these services and then I could get my children back.*

*The next day, the caseworker told me to go to court. She took the very same paperwork that we filled out together and made it into a petition under Article Ten of the New York Family Court Act.<sup>25</sup> I told them I was sincerely in need of help, and this was interpreted as, “You are guilty, these are the services you need, and something is wrong with you if you can't see that.”*

*I had told the caseworker about the help I needed when she first came to my home, in 2018, and yet she didn't offer me any services. Why were these services not offered when I asked the first time around? Why wasn't I given preventative services when I asked for them? Now, after a second call, after you have removed my children, you want to give me your services. I never knew that they were secretly interrogating me.*

#### IV. A VISION FOR FUNDAMENTAL CHANGE AND REFORMS TO SHRINK THE SYSTEM

As Ms. Frunel's experience demonstrates, there are multiple ways in which the system is currently failing to support parents labeled as having a disability. It is in this context that we seek an alternative model for family well-being. We seek a model that is non-adversarial and support-based. This call for a supportive rather than punitive system borrows both from the Disability Justice movement and the Movement for Black Lives. According to the Disability Justice primer *Skin, Tooth, and Bone: The Basis of Movement is Our People*, “We work to meet each other's needs as we build

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<sup>25</sup> N.Y. FAM. CT. ACT § 1101 (setting forth the procedures for “child protective” intervention and proceedings, including the petition).

toward liberation, without always reaching for state solutions which inevitably extend state control further into our lives.”<sup>26</sup> Likewise, the Movement for Black Lives demands “investments in the education, health and safety of Black people, instead of investments in the criminalizing, caging, and harming of Black people.”<sup>27</sup> Inspired by these movements, our vision for a system that truly supports families involves direct investment in communities of color and those with disabilities.

A system based in support would also make use of principles well understood in the disability community. Supported Decision-Making,<sup>28</sup> for example, draws on the idea that all people, regardless of disability status, require and are entitled to support, and that meaningful support of those who might not otherwise be deemed capable of making their own decisions will make real concepts of legal capacity.<sup>29</sup> The central idea in these frameworks is meaningful interdependence that does not penalize the individual for seeking support or supplant individual autonomy to decide on the specific sources of support that they need and desire. The authors urge the adoption of a system that genuinely supports existing family units. The use of family- or community-based supports is rooted in trust that families themselves know what they need.

Even as we call for a radically different system, we recognize that there is much standing between a true re-envisioning of the system and the current adversarial system that exists within the carceral state. What follows here, then, are proposals for reform. In making these suggestions, we are mindful of the long-standing call for “non-reformist reforms” and have endeavored to offer such reforms.<sup>30</sup> The following proposals are offered with knowledge and conviction that reduction of violence to communities of color requires shrinking, not merely reforming, the carceral state. Nonetheless, as so many parents remain caught in the system, we believe these reforms are vital. These reforms connect to Ms. Frunel’s

<sup>26</sup> DISABILITY JUSTICE PRIMER, *supra* note 5, at 25.

<sup>27</sup> *Invest-Divest*, MOVEMENT FOR BLACK LIVES, <https://m4bl.org/policy-platforms/invest-divest/> [<https://perma.cc/8N94-G3GS>] (advancing the policy platform of “investments in Black communities, *determined* by Black communities, and divestment from exploitative forces”) (emphasis added); *see also* Dorothy Roberts, *Abolishing Policing Also Means Abolishing Family Regulation*, IMPRINT, <https://imprintnews.org/child-welfare-2/abolishing-policing-also-means-abolishing-family-regulation/44480> [<https://perma.cc/8Z7J-FMMC>] (“Rather than divesting one oppressive system to invest in another, we should work toward abolishing all carceral institutions and creating radically different ways of meeting families’ needs.”).

<sup>28</sup> Supported decision-making is an emerging practice by which persons with intellectual, developmental, cognitive, and psychosocial disabilities can make their own decisions with the support of trusted persons in their lives. Kristin Booth Glen, *Supported Decision-Making from Theory to Practice: Further Reflections on an Intentional Pilot Project*, 13 ALB. GOV’T L. REV. 94, 98 (2020).

<sup>29</sup> *See, e.g.*, Robert Dinerstein, *Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making*, 19 HUM. RTS. BRIEF 8, 9 (2012).

<sup>30</sup> We understand the much-discussed concept of “non-reformist reform” as “reform focused on reducing the scale, power, tools, and legitimacy of the carceral state.” Amna A. Akbar, *Demands for a Democratic Political Economy*, 134 HARV. L. REV. F. 90, 101 (2020) (citing various examples highlighting “decades of campaigns against carceral infrastructure”). At the same time, we are mindful that “reform projects are contradictory gambits if the aim is transformation: they always have the possibility of reifying the status quo.” *Id.* at 103.

experience and to our collective observations of the harms perpetuated by the current family regulation system.

#### A. Pretrial Representation

The first of the three reforms that we suggest today would mandate that all parents be provided with pretrial representation. Parents deserve and need legal representation from the moment that ACS appears at their doorstep, makes a phone call to their child's school, or otherwise begins an investigation of abuse or neglect. As Ms. Frunel's experience demonstrates, without representation in these early stages, parents can both misapprehend the stakes of the investigation and proceed under the false impression that there are no possible punitive outcomes associated with the investigation. Just as likely, parents may not be aware that they have the right to exclude a caseworker from their home, to speak to a lawyer before consulting with a caseworker, to refuse an interview of their child, or any number of other possibilities.<sup>31</sup>

Access to pre-petition representation is especially important for parents with disabilities. Parents with disabilities, at least as much as any others, need to understand that they are not at the whim of Child Protective Services ("CPS"). Moreover, as Ms. Frunel's case reveals, decisions on whether or how to discuss concerns about mental health or other disabilities are complicated, nuanced ones that should be made with the consultation of an attorney who is well-versed in the relevant law and has experience navigating the ableism of the system. Notice of their rights at the outset is integral for all parents, but especially parents with disabilities.

At present, the vast majority of jurisdictions that provide legal representation for parents accused of abuse or neglect do not make this representation available for parents until after a petition is filed in court and the parent appears before a judge.<sup>32</sup> This puts parents at a grave disadvantage, often leading them to make statements under the mistaken impression that the child protective investigator is there to help or support them, not to build a legal case that may well be used to remove a child from their care or otherwise intervene into their family life. Moreover, it often

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<sup>31</sup> Courts have held that caseworkers' entry into families' homes, and even caseworkers' investigations involving children outside of their homes, is subject to the Fourth Amendment right against unreasonable searches and seizures. *See, e.g.*, *Gates v. Tex. Dep't of Protective & Regulatory Servs.*, 537 F.3d 404 (5th Cir. 2008) (caseworkers' warrantless entry into homes to investigate child abuse); *Calabretta v. Floyd*, 189 F.3d 808 (9th Cir. 1999) (same); *Schulkers v. Kammer*, 955 F.3d 520, 533–38 (6th Cir. 2020) (social workers' warrantless in-school interviews of children). *See also* Doriane Lambelet Coleman, *Storming the Castle to Save the Children: The Ironic Costs of a Child Welfare Exception to the Fourth Amendment*, 47 WM. & MARY L. REV. 413, 471 (observing that the federal circuit courts "agree that maltreatment investigations constitute Fourth Amendment 'searches' and 'seizures'"). *But see id.* at 430–31 (observing and problematizing the fact that over ninety percent of investigations are conducted with the parents' apparent consent, contending that most families do not know that they have the right not to talk to investigators).

<sup>32</sup> *See, e.g.*, N.Y. FAM. CT. ACT § 262 (2019) (requiring parents to appear in court to have an attorney assigned).



means that parents lack representation for the “days, weeks, or sometimes months after having their children taken into state custody.”<sup>33</sup>

Access to pre-petition legal services would also allow parents the opportunity to begin to solve legal problems in ways that might prevent the need for the involvement of the family regulation system in the first place, for example by securing public benefits or access to shelter. As the 2021 Call to Action from the nonprofit organization Children’s Rights recently articulated, representation for parents at the outset of an investigation could not only “significantly reduce and protect against the unnecessary involvement of Black families in the child welfare system,” it would “also ensure that Black parents’ voices are heard during an investigation.”<sup>34</sup>

Though some states have taken a more expansive view of a parent’s right to counsel, providing for example that a parent has a right to consult a lawyer from the very outset of a case,<sup>35</sup> parents do not typically learn of their right to a lawyer until after appearing in court. Fortunately, there are signs that more jurisdictions will begin to offer pre-petition representation. In June 2020, the Trump White House issued an Executive Order requiring federal guidance to states “regarding flexibility in the use of federal funds to support and encourage high-quality legal representation for parents and children, including pre-petition representation.”<sup>36</sup> The Executive Order highlights that this measure would not only work to prevent removals and work towards reunification but also “ensure that [parent] voices are heard and their rights are protected.”<sup>37</sup> Likewise, the New York State Office of Indigent Legal Services (“ILS”) has identified representation during CPS investigations as a best practice.<sup>38</sup> A recent

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<sup>33</sup> Funding Announcement, N.Y. State Off. of Indigent Legal Servs., Second Upstate Model Family Representation Office Grant: Request for Proposals 10 (Apr. 6, 2021) [hereinafter Request for Proposals], <https://www.ils.ny.gov/files/RFP-Second%20Upstate%20Model%20Family%20Representation%20Office%20Grant%20040621.pdf> [<https://perma.cc/BY7W-JDA8>] (citing MARY B. GOODHUE, JULES KERNES & CONSTANCE R. WARDEN, U.S. DEP’T OF HEALTH & HUM. SERVS., NO. 126665, CHILD PROTECTION AND THE FAMILY COURT: A STUDY OF THE PROCESSES, PROCEDURES, AND OUTCOMES UNDER ARTICLE TEN OF THE NEW YORK FAMILY COURT ACT 131–32 (1989)) (presenting context for the importance of family representation offices providing “timely” legal representation to parents in child protective proceedings).

<sup>34</sup> *Fighting Institutional Racism at the Front End of the Child Welfare Systems: A Call to Action to End the Unjust, Unnecessary, and Disproportionate Removal of Black Children from Their Families*, CHILDREN’S RTS. 18 (2021), <https://www.childrensrts.org/fighting-institutional-racism-at-the-front-end-of-child-welfare-systems/> [<https://perma.cc/MKG5-R4JB>]; see also *id.* at 29 (“These services should be independent from the child welfare agency, should not rely on referrals from the agency for locating families in need of services, and should not result in any additional monitoring of the family by the agency.”).

<sup>35</sup> See *id.* at 20 (presenting an overview of certain states’ constitutional law more expansively guaranteeing the right to counsel for parents).

<sup>36</sup> Exec. Order No. 13,930, 85 Fed. Reg. 38,741 (June 24, 2020); see also ADMIN. FOR CHILD. & FAMS., U.S. DEP’T OF HEALTH & HUM. SERVS., ACYF-CB-IM-21-06, UTILIZING TITLE IV–E FUNDING TO SUPPORT HIGH QUALITY LEGAL REPRESENTATION FOR CHILDREN AND YOUTH WHO ARE IN FOSTER CARE, CANDIDATES FOR FOSTER CARE AND THEIR PARENTS AND TO PROMOTE CHILD AND FAMILY WELL-BEING 7, 10–11 (Jan. 20, 2021), <https://www.acf.hhs.gov/sites/default/files/documents/cb/im2106.pdf> [<https://perma.cc/4GNM-FQM4>].

<sup>37</sup> Exec. Order No. 13,930, 85 Fed. Reg. 38,741 (June 24, 2020).

<sup>38</sup> N.Y. STATE OFF. OF INDIGENT LEGAL SERVS., STANDARDS FOR PARENTAL REPRESENTATION IN STATE INTERVENTION MATTERS 7–8 (2015), <https://www.ils.ny.gov/>

funding announcement from ILS to create the second of two model family representation offices requires the model office to provide representation to parents during investigations.<sup>39</sup>

### B. Family *Miranda*

Hand-in-hand with parents' right to timely representation is parents' right to be warned, at the outset of the investigation, of the stakes and consequences of the investigation, as well as their rights to decline to participate and to speak with a lawyer. Legislation establishing a so-called Family *Miranda* warning would require state agents and case workers to communicate to parents their rights at the start of a CPS investigation, including their right to an attorney.<sup>40</sup>

Like pre-petition representation, a Family *Miranda* warning at the outset of an investigation would empower parents to meaningfully exercise their rights and to take on active, confident roles in their representation. A warning would give them greater knowledge of their rights and a stronger voice in child protective proceedings. A Family *Miranda* warning would be specifically impactful for parents with disabilities who, because of the lengthy history of discrimination in our country, may have been given fewer opportunities to act as autonomous individuals who make their own decisions.<sup>41</sup> Significantly, there is no financial cost to requiring that parents be informed of their rights, and any such legislation would not lead to the creation of new rights. Instead, a Family *Miranda* warning would allow parents to know and understand the contours of their interaction with the state and would prevent against affirmative or tacit misrepresentations by case investigators.

Any movement for requiring a Family *Miranda* warning in child protective investigations will likely need to be legislative in nature because courts have been less than receptive to recognizing it as a constitutional requirement.<sup>42</sup> During the 2020–2021 New York State legislative session, the Parent Legislative Action Network advocated for legislation that would require a Family *Miranda* warning to be provided orally and in writing to parents and caretakers who are the subject of a CPS investigation. The bill

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files/Parental%20Representation%20Standards%20Final%20110615.pdf [https://perma.cc/E43E-KLLR].

<sup>39</sup> Request for Proposals, *supra* note 33, at 11.

<sup>40</sup> As referenced in the subheading to this Section, the concept is based on similar rights in criminal cases established by the U.S. Supreme Court in *Miranda v. Arizona*, 382 U.S. 436 (1966); see also Urban Matters, *Why a Child Welfare 'Miranda Rights' Law Is Essential: A Q&A with Advocate and Organizer Joyce McMillan*, NEW SCH. CTR. FOR NYC AFFS. (June 2, 2021), <https://www.centrernyc.org/urban-matters-2/2021/6/2/why-a-child-welfare-miranda-rights-law-is-essential-a-qampa-with-advocate-and-organizer-joyce-mcmillan> [https://perma.cc/WC4Q-HTCF].

<sup>41</sup> See, e.g., Kristin Booth Glen, *supra* note 28, at 120 ("Education for young people with [intellectual and development disabilities ("I/DD")] seldom includes explicit instruction on making decisions; rather, to the extent that a stated goal is self-determination, the emphasis is on "goals," often with professionals and/or family members making the decisions thought necessary for the person with I/DD to reach those goals.")

<sup>42</sup> See, e.g., *In re M.H.*, 163 Ohio St.3d 93, 2020-Ohio-5485, 168 N.E.3d 439 (finding that questioning by child abuse investigator did not violate suspect's *Miranda* or federal due process rights, because investigator was neither a law enforcement officer nor acting under direction or control of police, and confession obtained was not causally related to any conduct of police).

was introduced in both the State Senate and Assembly, but did not pass this session.<sup>43</sup>

### C. Independent Review Board

We advocate for the creation of a unit, housed outside of the family regulation system, to receive complaints about caseworkers and failures of the system. At present, complaints made about a specific caseworker, foster care agency, or other actor in the system are funneled through other employees and staff of the very same agencies about which the complaint is focused. For example, in New York City, ACS advises parents who do not believe their rights are being respected to first “talk to your ACS caseworker, your foster care caseworker or social worker.”<sup>44</sup> Other options are to “contact the ACS Office of Advocacy and make a complaint” or to speak to one’s own lawyer.<sup>45</sup> In Tennessee, the Department of Children’s Services (“DCS”) advises parents to raise complaints with “respect to infringement of . . . rights” to the DCS Customer Relations Unit.<sup>46</sup> These internal avenues for complaints leave open the real possibility of bias in the review and handling of complaints. Parents may also have concerns about the potential for retributive or punitive responses by particular caseworkers if and when a complaint is made. Moreover, there is little transparency in how these complaints are handled.

Our vision for an independent review board in the family regulation system is inspired by the New York City Civilian Complaint Review Board (“CCRB”), an independent agency “empowered to receive, investigate, mediate, hear, make findings, and recommend action on complaints against New York City police officers.”<sup>47</sup> Among the primary goals of the CCRB is to conduct investigations impartially.<sup>48</sup> To that end, the CCRB is composed entirely of civilian employees. It endeavors to investigate all allegations of misconduct and recommend “fair and appropriate” disciplinary actions whenever misconduct is found.<sup>49</sup>

Recent criticism of the CCRB has noted a “fatal flaw” in the oversight process: though the agency is entirely made up of civilians, the NYC Police Commission has total authority to disregard the CCRB’s disciplinary recommendations.<sup>50</sup> We believe that an effective independent

<sup>43</sup> S.5484-A, 2021–2022 S. Reg. Sess. (N.Y. 2021); A.6792, 2021–2022 Assemb. Reg. Sess. (N.Y. 2021).

<sup>44</sup> *Know Your Rights*, NYC ADMIN. FOR CHILD. SERVS., <https://www1.nyc.gov/site/acs/youth/know-your-rights.page> [<https://perma.cc/3WJ3-FDUK>].

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

<sup>46</sup> TENN. DEP’T OF CHILD. SERVS., CLIENT’S RIGHTS HANDBOOK 4 (2016), <https://janespokesup.com/wp-content/uploads/2019/03/TN-DCS-Client-Rights-Current.pdf> [<https://perma.cc/2HQ7-Q2ME>]; *Customer Relations*, TENN. DEP’T OF CHILD. SERVS., <https://www.tn.gov/dcs/contact-us/customer-relations.html> [<https://perma.cc/EXT5-M4MY>].

<sup>47</sup> *About CCRB*, NYC CIVILIAN COMPLAINT REV. BD., <https://www1.nyc.gov/site/ccrb/about/about.page> [<https://perma.cc/5GDY-4685>].

<sup>48</sup> *Id.*

<sup>49</sup> *Id.*

<sup>50</sup> *E.g.*, Carlton Brown et al., *Putting ‘Civilian’ Back in the Civilian Complaint Review Board*, CITY LIMITS (Dec. 18, 2020), <https://citylimits.org/2020/12/18/opinion-putting-civilian-back-in-the-civilian-complaint-review-board/> [<https://perma.cc/DA8Q-PJFA>] (noting that over the past two decades, the NYPD has “reduced or rejected the CCRB’s recommendations for serious discipline in about 71 percent of 6,900 serious misconduct charges that have been brought against officers”).

review board charged with oversight of the child protective investigators and foster care agencies would not only need to be fully independent in its staffing but also have the power to mete out appropriate, fair discipline in the event of misconduct.

The creation of such an independent board would allow parents with and without disability to confidently report concerns about violations of their rights or about other inappropriate behavior, without fear of bias or retribution. For parents with a disability, or those labeled as having a disability, an independent board would be a safe and secure place to report concerns of discrimination, inappropriate medicalization of disability, or wrongful denial of accommodations. To ensure that the board itself would not perpetuate ableist standards, it would be necessary to carefully train board members and to ensure that persons with disabilities are well represented on the board. An independent review board charged with overseeing the behavior of foster care agency staff and caseworkers could transparently handle complaints and create greater accountability among these actors.

#### V. CONCLUSION

We imagine a system where parents labeled as having a disability who seek support or assistance are not punished for their differences and their needs, but are instead supported. We seek not just the inclusion of parent voices but the centering of parent experiences, and respect for their intimate knowledge of their own and their children's needs in the creation of social supports. The reforms we briefly outline here are only the beginnings of larger change and are far from the total reimagination that we believe is necessary to realize a radically different system of support. A true reimaging of the family regulation system for parents with disabilities or those labeled as having a disability will require reckoning with ableism inherent in the system and embracing the Disability Justice framework. We envision a system of support that is organized around "leadership of those most impacted" and a recognition that "access needs aren't shameful."<sup>51</sup> Indeed, meaningful, non-punitive support for parents, especially parents with a disability label, will mean that "we can ask that our needs be met without compromising our integrity, we can balance autonomy while being in community, we can be unafraid of our vulnerabilities, knowing our strengths are respected."<sup>52</sup>

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<sup>51</sup> DISABILITY JUSTICE PRIMER, *supra* note 5, at 23, 26.

<sup>52</sup> *Id.* at 26.