



November 13, 2023

Submitted via regulations.gov

Melanie Fontes Rainer, Director
Office of Civil Rights
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Re: Notice of Proposed Rulemaking on Discrimination on the Basis of Disability in Health and Human Service Programs or Activities. Docket No: 2023-19149, RIN: 0945-AA15

Dear Director Fontes Rainer:

The Child Welfare League of America (CWLA) thanks the Department of Health and Human Services (HHS) and the Office for Civil Rights (OCR) for the Notice of Proposed Rulemaking regarding protecting the rights of parents, caregivers, foster parents, and prospective parents with disabilities involved in the child welfare system.

CWLA is a coalition of hundreds of private and public agencies that since 1920 has worked to serve children and families who are vulnerable. Our expertise, leadership and innovation on policies, programs, and practices help improve the lives of millions of children across the country. Our impact is felt worldwide.

It is vitally important that child welfare agencies adequately address disabilities in cases that are open so that case planning and service delivery are responsive throughout the life of the case. The CWLA National Blueprint for Excellence in Child Welfare, which serves as the foundation and framework for achieving the vision *that all children will grow up safely, in loving families, with everything they need to flourish—and with connections to their culture, ethnicity, race and language*, recommends “nondiscrimination policies that may be broader than legal requirements when they are felt to be in the best interest of child well-being, and encourages all entities and jurisdictions to work toward the adoption of policies that are inclusive and protect all those served from discrimination. Each entity must determine the applicability of relevant laws, and the entities should work together to protect all children, youth, and families from discrimination on the basis of race, color, age, **disability**, gender, familial status, religion, sexual orientation, gender identity, genetic information, language, religion, national, ethnic or social origin, political beliefs, or citizenship.”¹

¹ *The National Blueprint for Excellence in Child Welfare*. Child Welfare League of America. Pp 108-110.



Because of our commitment to nondiscrimination and our vision for the safety, wellbeing, and connectedness of all children, CWLA overall supports the Proposed Rule 88 FR 63392, with caveats and questions for HHS, as outlined below.

The proposed rule states or implies, in multiple places, that it is the fault of child welfare for withholding or not providing services that would enable families to remain together or be reunified or would allow individuals with disabilities to provide family foster care services for children who have been separated from their families. While we do not deny that many child welfare agencies and systems can and should do better in ensuring that children and caregivers have the supports and tools needed to be successful, it is also true that some families end up at the door of the child welfare agency (or the juvenile justice system) in order to access vital services that are simply not available in the community. Child welfare cannot be the only entry point to disability services for families that are our most vulnerable. The goal must be to prevent families from ever turning to child welfare by addressing this lack of available services and moving supports further upstream.

Additionally, while child welfare must do its part, the child welfare system alone cannot solve structural barriers to full implementation of the Americans with Disabilities Act (ADA). For instance, in rural areas, these services may be out of reach of families who would have to drive hours to access them, which is a burden both financially and practically. In urban and suburban areas, even if the services exist, there may be long wait lists due to a lack of qualified providers, or a lack of providers that accept Medicaid. In both rural and urban areas, there is a lack of services that offer language capacity beyond just English and Spanish, and culturally competent services can be difficult to find.

This lack of capacity, accessibility, and availability of appropriate services hinders child welfare's efforts to effectively serve adults and children with disabilities. **CWLA inquires whether the Department of Health and Human Services' Office of Civil Rights and Children's Bureau will issue guidance, jointly or separately, to help states better coordinate the relevant agencies and services to address the gaps in their systems.**

Additionally, CWLA inquires whether HHS will enforce rules and laws that require the Substance Abuse and Mental Health Services Administration (SAMHSA) to ensure there is a robust array of mental and behavioral health services available in the community, and that this array is accessible to children prior to involvement with the child welfare or juvenile justice systems.

CWLA has undertaken an environmental scan to determine state implementation of the Olmstead Act, which requires all states to have an "Olmstead Plan." An Olmstead Plan is a "public entity's plan for implementing its obligation to provide individuals with disabilities opportunities to live, work, and be served in integrated settings" (ADA.gov, n.d.). These plans set forth the existing system challenges and lay out specific action steps. Our analysis has found that many states do not have plans and that there are significant gaps in services for both children and adults.



Additionally, Olmstead Plans for adults often do not address whether or not the adult is also a parent and do not include family services.

CWLA inquires whether HHS’s relevant offices will issue guidance to push states to come into compliance with the requirements of the Olmstead Act.

Limitations of Federal Data

“According to data submitted to the Administration for Children and Families (ACF) through its Adoption and Foster Care Analysis and Reporting System (AFCARS) as reported in November 2021, more than 216,838 children entered the U.S. foster care system due at least in part to safety concerns related to parental fitness during 2020. Thirteen percent, or 28,771 children, were removed from a parent or caregiver based, in part, on “Caretaker Inability to Cope Due to Illness or Other Reasons” (pp. 21-22, c. 3)

A limitation of the AFCARS data collection is that it does not further differentiate the reasons for a child’s entry into foster care, including the severity of the conditions present at the time of removal, which impacts the decision of the caseworker and supervisory team. Often it is not the disability of the caregiver or child itself that is grounds for removal, but rather the impact of the disability on the individual that makes it impossible for a child to remain in their home. This decision-making process requires individualized assessment, good practice engagement, and a well-equipped and well-supported workforce in the child welfare agency.

This limitation in the data becomes particularly relevant when considering the complexity and challenges of decision-making where there are multiple factors affecting family functioning, including parental substance use. Research indicates that when parental substance use is present, there may be greater rates of intervention and separation than is strictly necessary based on the safety and wellbeing of the child, highlighting the need for additional education, training, and support for child welfare investigators and Response Workers. Under ADA guidelines, in order for substance abuse to count as a disability, it must be a diagnosed substance use disorder, and limited protections are offered for individuals recovering or in recovery from a substance use disorder.²

The National Center on Substance Abuse and Child Welfare (NCSACW) has operated since 2002. Joint funding comes from Children’s Bureau (CB), Administration for Children and Families (ACF); and the Substance Abuse and Mental Health Services Administration (SAMHSA), the Center for Substance Abuse Treatment (CSAT), and the Center for Substance Abuse Prevention (CSAP). NCSACW provides excellent training, technical assistance, and support for child welfare agencies to better respond to and address parental substance use and

² “Is Addiction a Disability? ADA Protections & Disability Benefits.” American Addiction Centers. Retrieved from: <https://americanaddictioncenters.org/rehab-guide/addiction-disability>



child safety and wellbeing. In light of the need for front line and supervisory staff to better understand and address parental substance use through a disability perspective, **CWLA inquires whether the Children’s Bureau and SAMHSA will utilize NCSACW’s technical expertise and array of resources to further share this information at the state level and to assist child welfare agencies in integrating disability nondiscrimination policies into practice.**

Reasonable Accommodations for Parents With Disabilities in the Child Welfare System

The proposed rule seeks to “*demonstrate the need for rulemaking to clarify child welfare entities’ nondiscrimination obligations under the Rehabilitation Act. The numerous and diverse range of issues raised in complaints received by OCR show that covered child welfare entities need specific articulation of their longstanding obligations under section 504.*”

There are, of course, states that have disability nondiscrimination policies that could serve as models for this articulation. Some states are changing their laws about parents so that they are more like the ADA, like Idaho, Maryland, Massachusetts, Arkansas, Nebraska, and West Virginia.³ For example, the Massachusetts Department of Children and Families’ (DCF) disability policy includes reasonable accommodations for parents that follow precedent set by employment rights, using the same fundamental principles.⁴ The Department uses a collaborative process in which families state that the caregiver or child has a disability and they are believed - the caseworker then operates on the assumption that they do in fact have that disability and no testing is required to prove it. There is a process for identification of reasonable accommodations, a process for appeals, and families and caseworkers have access to legal and clinical specialists to guide and assist them throughout their involvement with the agency.

The Massachusetts DCF policy outlines the process by which the department must determine and provide reasonable accommodations for parents and caregivers with disabilities and specifies that they ought to be included in any planning: “The parent/caregiver can be helpful in determining what accommodation will work for them. People with disabilities are the experts on their own disability and the kinds of accommodations, supports, and services that may be most helpful.” The decision-making team can include specialized agency staff including a Regional Disability Liaison and/or Disability Specialist to help ensure the best possible agreement is reached. However, the policy also notes that there are limitations to what the Department must provide: “The Department is not required to provide parents/caregivers with personal devices or devices that must be prescribed (e.g., wheelchairs, eyeglasses, or hearing aids) or substantial assistance of a personal nature (e.g., assistance dressing or using a toilet).” While the Department has discretion and is able to use its funding to provide a number of items and services to accommodate disabilities, particularly for children, it should be the responsibility of other child-

³ “State Laws- Parents with Disabilities – Summary.” National Research Center for Parents with Disabilities. Retrieved from: <https://heller.brandeis.edu/parents-with-disabilities/pdfs/summary-state-legislation-1a.pdf>

⁴ Disability Policy. Massachusetts Department of Children and Families. Pp. 7-13. Effective March 31, 2023. Retrieved from: <https://www.mass.gov/doc/dcf-disability-policy/download>



serving systems to provide these services, and the caseworker is encouraged to collaborate with other services providers to attend to these needs.

CWLA inquires if OCR and the Children’s Bureau will issue guidance to states that further clarifies what should be included in policies for reasonable modifications, and technical assistance in implementing such policies.

Residential and Congregate Care

“Title IV–E agencies accept billions of dollars from HHS to provide safe foster care placements for children and youth who cannot remain in their homes. As a condition of receiving these funds, child welfare entities must comply with Federal child welfare law and disability rights laws that require agencies to place foster children and youth in the least restrictive and most family-like setting appropriate to their needs. Congregate care should never be considered the most appropriate long-term placement for children, regardless of their level of disability. This stance is reflected in the Federal enforcement of the integration mandate.” (p. 24)

In the Proposed Rule, OCR rightfully highlights that children should reside in the most integrated settings in foster care, which largely means that children should reside in a family or family-like setting in lieu of residential facilities whenever possible. CWLA firmly supports this requirement; when a child must be separated from their family of origin, they should be cared for by a kin or relative, or else by another foster family. We know that children and youth have better outcomes when they are able to live in a family or family-like setting. However, **CWLA urges HHS to reconsider the language used here, that congregate care should *never* be considered the most appropriate setting.**

The term “disabilities” is a broad umbrella, with several types of diagnoses that qualify within the designation, including autism, mental health diagnoses, and Fetal Alcohol Spectrum Disorder (FASD). There may be times when children with diagnoses like the ones listed require a level of treatment that necessitates a stay in a residential treatment facility. When this is the case, the goal is that the child remains in the residential setting for the shortest amount of time possible and that the transition back to the community and to a family home (foster or otherwise) be made as quickly and smoothly as possible. Absolute language, such as this comment about congregate care never being most appropriate, is unhelpful and puts further strain on families and the child welfare system to provide care without access to appropriate and necessary services. When children can’t access the level of care that they need when they need it, it can result in a lack of stable placements, with children being moved from home to home as the agency is unable to meet the needs of the child and the caregiver - this lack of stability can cause further trauma and pain to the child.

CWLA inquires whether HHS will further clarify the role of residential treatment within the array of services and supports for children with disabilities.



Child Welfare Questions

The Department has included three questions related to child welfare services, soliciting comments on these particular provisions. CWLA offers recommendations and suggestions for these inquiries below.

Child Welfare Question 1: “The Department seeks comment on additional examples of the application of the most integrated setting requirement to child welfare programs and welcomes comments on any additional points for consideration regarding integration of children with disabilities in child welfare contexts.”

The most integrated setting for a child with a disability is the most homelike setting appropriate to meet the child’s needs, and there is a presumption that the most integrated setting is a family setting, when possible. As noted above, identifying appropriate supports and accommodations to preserve and reunify families should be a collaborative process in which the child and family’s preferences are taken into account and both the family and the caseworker have access to specialists to guide and support decision-making.

We suggest that the Department consider some of the recommendations and points the Justice Department raised in their 2015 letter to the State of West Virginia,⁵ which has been referenced in this NPRM. Among the recommendations to the Governor’s office DOJ proposed:

“A policy, practice, and regulations should ensure that a single Intensive Care Coordinator has ultimate responsibility and accountability in cases where a child is involved in multiple child-serving systems (such as child welfare, juvenile justice, Medicaid, and special education).”

CWLA notes that this Intensive Care Coordinator must sit outside of the child welfare agency in order to facilitate this coordination most effectively and to safeguard against this coordination becoming the sole responsibility of the child welfare agency, resulting in less accountability and responsibility placed on other child- and family-serving systems involved.

“The state should expand in-home and community-based mental health service capacity throughout the state to minimize or eliminate unnecessary institutionalization, prolonged institutionalization, and heightened risk for institutionalization, and to reduce the risk youth with disabilities will end up in settings that are not designed to provide mental health care, such as detention centers, correctional facilities, and jails.” CWLA notes that this expansion of in-home and community-based mental health service capacity would also minimize unnecessary involvement in the child welfare system, both by serving as a protective factor against child maltreatment and by eliminating the need for families to access these services through the child welfare system.

⁵ Letter to Office of the Governor, The Honorable Earl Ray Tomblin, State of West Virginia, June 1, 2015, from U.S. Department of Justice, Civil Rights Division Office of the Assistant Attorney General, Washington, D.C.



“Comprehensive Centers should provide for (directly or indirectly) in-home and community-based mental health services across the state including Intensive Care Coordination, Crisis Response and Stabilization, In-home and Community-based Direct Services and Therapeutic Foster Care. Flexible services and support should be available in sufficient amount, duration, and scope to all children who need them to be successful in the community, including respite, transportation, and family/peer support.”

States should implement a cross-system remedial plan that ensures children and youth throughout the state, including children eligible for Medicaid, involved in the mental health, child welfare, juvenile justice and/or educational systems are not unnecessarily placed in segregated residential treatment facilities. This remedial plan should include outreach and educational programs for stakeholders including judges and other court personnel, law enforcement, educational personnel and others. It should specifically address the heightened risk factors experienced by status offenders with mental illness, older children and youth, children and youth with mental health and intellectual disabilities, LGBTQ children and youth, trauma exposed children, minority children, and children with prior placement histories.”

It must be noted again that many of the recommendations in this letter fall outside the scope of the services provided by child welfare agencies and rather are under the responsibility and authority of Medicaid and the mental and behavioral health service systems. The Massachusetts DCF Disability Policy specifies that, “ [t]he Department is not required to provide a requested accommodation or auxiliary aid or service if it would fundamentally alter the nature of the Department’s services or programs or is unduly burdensome administratively or financially.” It goes on to say that determining whether an accommodation can be denied on these grounds must be done in consultation with the department’s legal team. CWLA agrees with the Massachusetts policy in this determination and urges HHS and OCR to consider the scope of services offered by the child welfare system in finalizing and implementing this proposed rule.

Child Welfare Question 2: “The Department invites comment on this list of prohibited activities in the child welfare context, especially on whether commenters believe it is complete.”

“(a) Discriminatory actions prohibited. (1) No qualified individual with a disability shall, on the basis of disability, be excluded from participation in, be denied the benefits of, or otherwise be subjected to discrimination under any child welfare program or activity that receives Federal financial assistance. (2) Under the prohibition set forth in the previous subsection, discrimination includes: (i) Decisions based on speculation, stereotypes, or generalizations that a parent, caregiver, foster parent, or prospective parent, because of a disability, cannot safely care for a child; and (ii) Decisions based on speculation, stereotypes, or generalizations about a child with a disability. (b) Additional prohibitions. The prohibitions in paragraph (a) of this section apply to actions by a recipient of Federal financial assistance made directly or through contracts, agreements, or other arrangements, including any action to: (1) Deny a qualified parent with a disability custody or control of, or visitation to, a child; (2) Deny a qualified parent with a disability an opportunity to participate in or benefit from reunification services is



equal to that afforded to persons without disabilities; (3) Terminate the parental rights or legal guardianship of a qualified individual with a disability; or (4) Deny a qualified caregiver, foster parent, companion, or prospective parent with a disability the opportunity to participate in or benefit from child welfare programs and activities. (c) Parenting evaluation procedures. A recipient to which this subpart applies shall establish procedures for referring individuals who, because of disability, need or are believed to need adapted services or reasonable modifications, and shall ensure that tests, assessments, and other evaluation materials, are tailored to assess specific areas of disability-related needs, and not merely those which are designed to provide a single general intelligence quotient.”

CWLA finds the list above to be all-inclusive, outlining a reasonable expectation of nondiscrimination practice for child welfare agencies and contracted services. Child welfare agencies abiding by this list of prohibited activities will better serve children and caregivers who have disabilities.

CWLA’s National Blueprint notes that, “in most instances, parents are uniquely qualified to advance the rights of children and to act in their best interest,” and that “the rights of children and parents are interconnected. It is the responsibility of every parent, family, and caregiver to recognize and protect children’s rights, and it is the responsibility of individuals and entities to work together to give families/parents optimum tools, supports, and opportunities so that they can fully assume responsibility for advancing the rights of their children.”⁶ Child welfare agencies must meet this minimum standard to ensure that parents and caregivers with disabilities are able to fully participate in child welfare services and programs.

Child Welfare Question 3: “The Department seeks comment on how agencies would implement these referral procedures, ensure that service providers use the methods described, and prohibit the use of IQ alone as the basis for a parenting assessment.”

As with any proposed reform, there are states and agencies that have already made significant changes and progress in addressing discrimination on the basis of disability, and we urge OCR and CB to look to these states as models for implementation of the proposed rule, when finalized.

For example, Massachusetts DCF employs and utilizes clinical and legal specialists within the department to provide support to the caseworkers, supervisors, and parents and caregivers when navigating disability accommodations and decisions. The following personnel are available and at times required to participate in consultation and decision-making:

Regional Disability Liaison is responsible for:

- Providing consultation to the clinical teams when requested or required;
- Assisting with, and participating in, meetings to discuss requested accommodations and auxiliary aids and services;

⁶ National Blueprint, p. 26.



- Receiving and resolving disability-related complaints, including complaints of disability discrimination; and
- Documenting discrimination complaints and resolution in the electronic record.

Statewide Disability Coordinator is responsible for:

- Providing consultation to the Department's staff when requested;
- Receiving and helping to resolve complaints of disability discrimination; and
- Documenting discrimination complaints and resolution in the electronic record.

Massachusetts DCF's policy explicitly states, "If a parent/caregiver has a disability, a determination that the parent/caregiver's disability impacts their ability to provide for and maintain child safety must be based on objective facts and not on stereotypes or generalizations about individuals with disabilities. For example: A parent's IQ score alone should not be relied on to determine that they cannot safely parent their child or are unable to learn certain parenting skills."⁷

The use of supervision and consultation with disability experts helps to ensure that Response Workers, Ongoing Caseworkers, and other direct service staff have the tools and resources needed to make accurate and fair determinations of safety and to fully include and incorporate parents and caregivers in the child welfare agency's services and programs.

CWLA inquires whether the relevant federal agencies will provide model policies and training and technical assistance for implementation based on states that have already made significant improvements in this area of practice.

Finally, it must be stated that the implementation of the policies and practices indicated in the proposed rule will rely on good social work practice from the child welfare workforce. Fair individualized assessments, competent decision-making, and respectful treatment of parents, caregivers, and children with disabilities happens at the level of the Response Worker and Ongoing Caseworker, the front line staff people that are often the least experienced, least resourced and lowest paid staff in the agency. Turnover and vacancy rates in child welfare agencies remain high, making it extremely difficult to maintain a well-trained and well-prepared workforce. Agencies can offer regular training on a variety of topics and procedures, but if staff continue to leave their roles at such high rates, it will be impossible to ensure that all investigators and caseworkers have the skills necessary to meet the standards laid out in this proposed rule.

System-wide policy reform is necessary and helpful, and leadership commitment to change is a useful starting point, but if reform is not embraced and practiced by individual staff, it will not have the intended impact on children and families. It is imperative that we address the turnover

⁷ Disability Policy, p. 16.



rate of child welfare staff and support both public and private agencies in recruiting and retaining high-quality and high-performing workers.

CWLA inquires whether HHS will dedicate thought, time, and resources to helping states, counties, territories and tribes in addressing the persisting workforce concerns that will stymie progress in disability nondiscrimination practice and in other reforms.

Conclusion

We thank HHS and OCR for the opportunity to offer these comments and questions in response to the Notice of Proposed Rulemaking regarding protecting the rights of parents, caregivers, foster parents, and prospective parents with disabilities involved in the child welfare system. As the nation's oldest and largest membership coalition of child welfare service providers, and as a national advocacy and standard-setting organization, CWLA supports the effort to strengthen disability nondiscrimination policy and practice, and we look forward to working with the relevant federal, state, and local partners in implementing meaningful reform to better serve children and families.