



November 13, 2023

Molly Burgdorf
U.S. Department of Health and Human Services, Office for Civil Rights
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue SW
Washington, DC 20201

Re: NPRM on Discrimination on the Basis of Disability in Health and Human Services Programs or Activities, Document Number: HHS-OCR 2023-0013-0001 RIN: 0945-AA15

Dear Section Chief Burgdorf:

Thank you for the opportunity to comment on the proposed rule to address [Discrimination on the Basis of Disability in Health and Human Services Programs or Activities](#) and update to Section 504 of the Rehabilitation Act regulations to ensure consistency with the Americans with Disabilities Act, the Americans with Disabilities Amendments Act, or the 1992 Amendments to the Rehabilitation Act. We are grateful for the Department's focus on addressing disability discrimination in the child welfare system. As your investigations cited in the preamble have demonstrated, many young people and families have faced disability discrimination in their contact with the child welfare system. The devastating results have included unnecessary family separation and harmful institutionalization.

Who We Are

The [Education Law Center-PA \("ELC"\)](#) is a non-profit legal advocacy organization that uses impact litigation, individual representation, and legislative and regulatory reforms to ensure and advance the rights of Pennsylvania's students who are most marginalized by our education system. Through our Helpline which receives approximately 1500 intakes each year and impact litigation we advocate for children living in poverty, Black and Brown students impacted by systemic and structural racism, children with disabilities, immigrant students, children experiencing homelessness, LGBTQ+ students, and children and youth impacted by involvement in the child welfare and/or juvenile justice system. Over our 45-year history, ELC has handled thousands of individual matters on behalf of children and youth in the child welfare system, with a particular focus on students living in residential settings who commonly receive an inferior education at on-grounds schools which undermines their ability to graduate and often deprives students with disabilities of their right to a free, appropriate public education under the *Individuals with Disabilities Education Act* ("IDEA") 20 U.S.C. 1400 *et seq.* and its

implementing regulation, 34 C.F.R. Part 300 and Section 504 of the Rehabilitation Act of 1973 (“Section 504”) and its implementing regulation, 34 C.F.R. Part 104.

As attorneys in education civil rights law, our advocacy seeks to expand educational opportunities and improve life outcomes for children impacted by the child welfare system. Our advocacy has included authoring several reports with policy recommendations to improve educational outcomes for youth who are system involved,¹ ensuring implementation of federal and state laws to ensure school stability and other rights for students in the child welfare system,² and developing state legislation to support students to graduate. We appreciate this opportunity to comment on the proposed regulations which will have a direct impact on our clients and the families we strive to serve.

Analysis and Recommendations

We appreciate the examples of discrimination in the preamble related to the placement and treatment of children in the child welfare system, including the emphasis on the improper use of group care. Our recommendations seek to ensure that additional prohibitions are clearly delineated in the proposed rule, the integration mandate is consistently upheld, and that the rule is informed by common and recurring circumstances of the foster care system.

1. Clarify that the Rule Includes Young People Receiving Child Welfare Services

We believe that the intention of the rule is to cover all young people who come into contact with the child welfare system and receive child welfare services. However, without further clarification, the use of the term “child” may be misinterpreted to include only minors receiving child welfare services when Title IV-E of the Social Security Act includes young people up until age 26 in some cases.³

Suggested Change:

We recommend that the word “youth” be added wherever the word child or children is mentioned to make clear that young people are included in the protection of the law if they are connected with the child welfare system. We propose the following definition for “youth”: *For the purposes of this section, youth means an individual under age 26 who is eligible for or receiving child welfare services pursuant to Title IV-E of the Social Security Act, including the John H. Chafee Foster Care Program for Successful Transition to Adulthood.*

¹ See, e.g., *Credit Overdue: How States Can Mitigate Academic Credit Transfer Problems for Youth in the Juvenile Justice System* (2020), <https://www.elc-pa.org/wp-content/uploads/2020/10/Credit-Overdue.pdf>; *Unsafe and Uneducated: Indifference to Dangers in Pennsylvania’s Residential Child Welfare Facilities*, (2018), https://www.elc-pa.org/wp-content/uploads/2018/12/2018_Pennsylvania-Residential-Facilities_Childrens-Rights_Education-Law-Center.pdf; Arley Styer, *Moving the Dial: A Report on Education Experiences of Children in Pennsylvania Residential Treatment Facilities* (Stoneleigh Foundation & Education Law Center 2011), https://www.elc-pa.org/wp-content/uploads/2013/08/access_Moving_the_Dial_Styer.pdf;

² See e.g., *Every Student Succeeds Act*, 20 U.S.C. 6311 *et seq.*

³ States can provide Chafee Independent Living services to youth who have been involved with the child welfare system up until age 23 and can provide Education and Training Vouchers under the Chafee Act until age 26. See 42 U.S.C.A. 677 (a)(4)& (i)(3).

In the alternative, we recommend that the rule define child as: *an individual under age 18 and young people age 18 and over who are eligible for child welfare services pursuant to 42 U.S.C.A. 675 (8) and 42 U.S.C.A. 677*. Either change will ensure that the proposed rule applies to young people in extended foster care and young people receiving Chafee services.

2. Include Agencies and Entities Providing Covered Services Through Contract and Agreements in Various Provisions of the Proposed Rule

While certain provisions of the proposed rule acknowledge that governmental services are provided by nongovernmental agencies through agreements and contracts the proposed rule does not do so consistently. This is a frequently issue with regard to the delivery of child welfare services, particularly in large urban settings. To ensure that all children, youth and families receive the full protection of the law, we recommend the following changes below in [blue](#).

Suggested Changes:

“Foster care means 24-hour substitute care for children [and youth](#) placed away from their parents or guardians and for whom ~~the~~ [a](#) State agency has placement and care responsibility, [either directly or through contracts, agreements, or other arrangements with another agency or entity](#). This includes, but is not limited to, placements in foster family homes, foster homes of relatives, group homes, emergency shelters, residential facilities, childcare institutions, and pre-adoptive homes. A child is in foster care in accordance with this definition regardless of whether the foster care facility is licensed and payments are made by the State or local agency for the care of the child, whether adoption subsidy payments are being made prior to the finalization of an adoption, or whether there is Federal matching of any payments that are made.”

3. Add Language to 84.60 (a) to Clarify Prohibited Actions that Result in Improper Institutionalization

As the preamble notes, children and youth in foster care are at high risk for being placed in group care and institutions. This is especially true for older youth in foster care with those with disabilities. Rather than building an appropriate continuum of care, including supports so children with disabilities can remain in their home of origin, many state and local child welfare agencies utilize institutions as the “default” placement, particularly for older youth with disabilities.

The recommendations below provide more specificity to ensure that children and youth with disabilities served by child welfare programs are afforded full and equal opportunities to access and benefit from community and family-based child welfare services and that the unnecessary, harmful, and unjustified segregation of children with disabilities in institutional and congregate care settings is recognized as discriminatory and in violation of the law. These recommendations also respond to the Department's request for comment on additional examples of the application of the most integrated setting requirement to child welfare placements and services.

Suggested Changes:

§ 84.60 (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 [or youth](#); and

(ii) Decisions based on speculation, stereotypes, or generalizations about a child [or youth](#) with a disability, [including but not limited to assuming that a child or youth cannot live in and benefit from a family setting in the community.](#)

[\(iii\) Initiating or consenting to the placement of a child in a segregated setting in a congregate care setting](#)

a. [when appropriate services or reasonable modifications would permit the child to live in their own family, home, or the home of a sibling, relative or kin, a foster or adoptive home, or a therapeutic foster home.](#)

b. [without conducting an individualized assessment of the most integrated setting appropriate to meet the child's needs.](#)

c. [without providing home- and community-based services⁴ and supports prior to initiating placement in a segregated setting.](#)

[\(iv\) Placing a child or youth in an institution or congregate care setting whenever home- and community-based services and supports would allow them to live in a more integrated less restrictive setting.](#)

[\(v\) Developing an array of placements that promotes or relies on institutions or congregate care facilities rather than an adequate continuum of community based placements for children and youth with disabilities.](#)

[\(vi\) Denying services and reasonable modifications to children and youth unless there is an imminent risk of harm to the child or youth from the specific modification or service, or providing such modification amounts to a fundamental alteration.](#)

⁴ “Home and community-based services” as used here are defined consistent with the American Rescue Plan Act to include any of the following: home health care; personal care; PACE; home and community-based services authorized under Social Security Act section 1915(b), (c), (i), (j), and (k); case management; rehabilitative services, including those related to behavioral health, described in Social Security Act section 1905(a)(19), and such other services specified by the Secretary of Health and Human Services. See [American Rescue Plan Act of 2021](#), Pub. L. 117–2 § 9817(a)(2)(B).

(vii) Determining the risk of harm to a child or youth using any analysis other than Section 504’s “direct threat” provision, which requires an individualized, fact-specific and context-specific analysis.

(viii) Placing a child or youth in an institution or congregate care setting due to the failure of their Local Education Agency to provide appropriate educational programs, services, and supports in their community.

4. *Add Language to 84.60 (b) to Clarify Prohibited Actions that Result in Improper Institutionalization and Removals*

Similar to recommendation #1, we recommend greater specificity in enumerating prohibited actions so that children and families are supported to remain together consistent with the law. The reasonable efforts’ requirement is a core legal requirement that ensures efforts are made to prevent removal and return a child home if they come into foster care. 42 U.S.C.A. 671 (a)(15)(B). If they cannot be returned home, reasonable efforts must also be made to finalize the child’s permanency plan. 42 U.S.C.A. 671 (a)(15)(E)(ii).

Suggested Changes:

(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 any and all services provided by a child welfare agency, including, but not limited to, family preservation and reunification services that are 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 child, youth, caregiver, foster parent, companion, or prospective parent with a disability the opportunity to participate in or benefit from child welfare programs and activities.
- (5) Fail to provide reasonable modifications as defined by [proposed] 45 C.F.R. 84.68 (b)⁵
- (6) to make reasonable efforts consistent with 42 U.S.C.A. 671 (a)(15) for a qualified child, youth, parent or guardian to prevent placement, return a child their parent or guardian, or to finalize the permanency plan.
- (7) Deny a qualified child or youth the opportunity to live in the most integrated setting appropriate to their needs. A setting includes any and all temporary or permanent settings in which a child or youth is placed by the child welfare agency at any and all points of the case.

⁵ See proposed 45 CFR 84.68(b)(7).

5. *Recommendations to Clarify the Most Integrative Setting and Reasonable Modifications*

We agree with the National Disability Rights Network that the most integrated setting for a child or youth with a disability is the most homelike setting appropriate to meet the child or youth's needs, and that there is a presumption that the most integrated setting is a family setting. A failure to provide home- and community-based services, including intensive services, is a violation of the integration mandate because it puts children and youth at serious risk of needless institutionalization or segregation. Decisions to place a child in a segregated setting that are based on speculation, generalizations, or stereotypes or without an appropriate individualized assessment are discriminatory.

HHS must require individualized assessments that are based on current medical knowledge and the best available objective evidence about the appropriateness of the child living with a family (e.g., parents, kin, foster family, therapeutic foster family, or adoptive family), and that include input from the Child and Family Team, including whether or not the child consents to the placement. Additionally, the child's personal preferences should be part of the consideration, when appropriate.

We also agree with NDRN that the child welfare community will greatly benefit from including the non-exhaustive, illustrative examples of reasonable accommodations listed below in the preamble.

For parents:

- Changes in frequency, duration, or location of parent-child visitation
- Hands-on training during a child's medical and early intervention services appointments
- Plain language training materials at appropriate literacy levels
- Adaptations in the manner in which specific training is conducted
- More frequent support from a social worker
- Assistance in understanding and applying behavioral supports for a child who needs these supports
- Training in how to attend IEP meetings and ensure that a child's educational needs are being met
- Modified action planning
- Assessment by a professional who is expert on working with parents with disabilities
- Other modified family preservation and reunification services⁶

For children:

- Case management and care coordination
- Basic medical needs for children who have complex medical conditions such as in-home nursing supports, hygiene supplies, common first aid and IV supplies, and durable medical equipment

⁶ U.S. Dep't of Health & Hum. Servs., U.S. Dep't of Justice, *Settlement between the U.S. Departments of Justice and U.S. Dep't of Health & Hum. Servs. and Massachusetts Department of Children and Families* (Nov. 19, 2020), https://archive.ada.gov/mdcf_sa.html, https://archive.ada.gov/mdcf_sa.html, https://archive.ada.gov/mdcf_sa.html.

- Services that enable children to live with their families and in supported kinship placements, including: parenting skills classes, household management training, peer support, homemaker services, respite, housing assistance, transportation, cultural brokers and community liaisons⁷
- For children with mental health or behavioral related needs:
 - Intensive services to decrease child safety needs, reduce risks, and keep children out of more expensive institutional care. These services include:
 - Intensive Care Coordination (Wraparound)
 - Intensive Home-Based Supports
 - Crisis Stabilization / Mobile Crisis
 - Therapeutic Foster Care

6. *Add Language to 84.60 (b) to Clarify Prohibited Actions Related to Educational Decisions for Youth in Foster Care*

Young people in the child welfare system, including youth with disabilities, face multiple educational challenges. One of the significant challenges that youth with disabilities in foster care face is being placed in sub-par educational settings, particularly when they are in a residential or group care placement. For example, ELC's survey of hundreds of young people and child welfare professionals in Pennsylvania found that large numbers of youth in foster care placed in residential settings languished in schools located on the grounds of residential facilities without grade appropriate instruction.⁸ Our subsequent publication, *Unsafe and Uneducated: Indifference to Dangers in Pennsylvania's Residential Child Welfare Facilities* further details how, when children and youth in foster care are placed in institutions, their educational rights, including the right of students with disabilities to receive appropriate and effective special education services and their right to be educated in the least restrictive environment, are at high risk for abuse or are lost altogether. In nearly all cases in Pennsylvania, children and youth in foster care are placed in private facilities that contract with state or county agencies and these educational programs receive little to no oversight, vastly increasing the likelihood that students will receive an inferior education and deprived of their right to a quality education.⁹ For these reasons, we believe adding the prohibitions listed below are necessary to ensure compliance with federal laws and protect against discrimination and protect the educational rights of children and youth in foster care.

⁷ Nat'l Council on Disability, *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and their Children*, 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://www.ncd.gov/sites/default/files/Documents/NCD_Parenting_508_0.pdf.

⁸ Arley Styer, *Moving the Dial: A Report on Education Experiences of Children in Pennsylvania Residential Treatment Facilities* (Stoneleigh Foundation & Education Law Center 2011), https://www.elc-pa.org/wp-content/uploads/2013/08/access_Moving_the_Dial_Styer.pdf.

⁹ *Unsafe and Uneducated: Indifference to Dangers in Pennsylvania's Residential Child Welfare Facilities*, https://www.elc-pa.org/wp-content/uploads/2018/12/2018_Pennsylvania-Residential-Facilities_Childrens-Rights_Education-Law-Center.pdf.

Suggested Changes:

(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:

(6) Deny a child or youth the opportunity to be educated in the least restrictive school environment that best meets their educational needs, including enforcing their right to attend the local public school or school of origin in accordance with state and federal law and for students with disabilities to be educated with non-disabled peers.

(7) Require children and youth in congregate care settings to disenroll from a public school or school of origin and enroll in onsite school without an individualized consideration in accordance with state and federal law

(8) Deny a child or youth the participation of their legally authorized educational decision maker regarding any decisions that impact the child or youth's educational placement, programming, and services.

(9) Deny a child or youth with disabilities a free, appropriate, public education, including the right of a youth to receive transition services beginning at age 16 or younger as required by state law.

7. Recommendation to Promulgate Rules to Clarify that Children and Youth Placed and Served through the Juvenile Justice System are Covered by Section 504

While the proposed rule addresses children, youth, and families who come into contact with the child welfare system, we strongly recommend that parallel rules be promulgated to cover the programs, services, and placements that youth in the juvenile justice system receive. In addition, large numbers of young people in the juvenile justice system have had experience in the child welfare system.¹⁰ The majority of violations related to the use of congregate care noted in the preamble to this proposed rule, also apply to youth involved in and impacted by the juvenile justice system. In addition, the large number of youth with disabilities in the juvenile justice system make the need for clarity about the application of section 504 all the more urgent. The Coalition for Juvenile Justice notes that studies show that 65 to 70 percent of youth involved with the justice system have a disability—that is three times higher than the rate compared to youth without disabilities.¹¹ Similar patterns have been noted in publications issued by the

¹⁰ For example, one research study examining data from New York City, Cuyahoga County, Ohio, and Cook County Illinois showed the following for percentage of youth in the juvenile justice system with child welfare involvement: 70.3%, 68.5%, and 44.8% respectively. Barbara Tatem Kelly & Paul A. Haskins, *Dual System Youth: At the Intersection of Child Maltreatment and Delinquency* 6 (National Institute of Justice), <https://www.ojp.gov/pdffiles1/nij/255646.pdf>.

¹¹ Leigh Ann Davis, *Youth with Disabilities in the Juvenile Justice System: a Nationwide Problem* (November 12, 2015), <https://www.juvjustice.org/blog/971#:~:text=One%20study%20reports%20that%2065,compared%20to%20youth%20without%20disabilities.>

Office of Juvenile Justice and Delinquency Prevention.¹² For the safety and well-being of youth in the juvenile justice system, we recommend that regulations on the application of section 504 to young people in the juvenile justice system are incorporated or separately promulgated.

Conclusion

Thank you for this opportunity to comment on the proposed rule. We appreciate the Department's commitment to addressing disability discrimination in the child welfare system which has resulted in children and youth with disabilities being subject to harmful family separation, institutionalization, and stripping children and youth of the robust protections of the federal laws under the IDEA and Section 504.

Sincerely,

A handwritten signature in cursive script that reads "Maura McInerney". The signature is written in dark ink and includes a small flourish at the end.

Maura McInerney, Esq.
(Pronouns: she/her)
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¹²See *Youths with Intellectual and Developmental Disabilities in the Juvenile Justice System* (2017), https://ojjdp.ojp.gov/model-programs-guide/literature-reviews/youths_with_intellectual_and_developmental_disabilities_in_the_juvenile_justice_system.pdf.