



June 30, 2022

Seth Galanter, Esq.  
Deputy Assistant Secretary for Legal Affairs  
U.S. Department of Education  
Office for Civil Rights  
400 Maryland Avenue, SW  
Washington, DC 20202

Dear Deputy Assistant Secretary Galanter:

The National Down Syndrome Society (NDSS) is the leading human rights organization for all individuals with Down syndrome. NDSS envisions a world in which all people with Down syndrome have the opportunity to enhance their quality of life, realize their life aspirations and become valued members of welcoming communities.

We write to respond to the Department of Education's call to the public requesting information for the purpose of amending the regulations implementing Section 504 of the Rehabilitation Act of 1973 (Section 504). NDSS is grateful to the Department for engaging members of the disability community on this critical topic. We are pleased to offer these written remarks to guide the Department and the Office of Civil Rights (OCR) in their initial fact-finding and exploration, and we will follow up with formal comments during the formal rulemaking process. Additionally, we were pleased to have supported Kayla McKeon, NDSS' Manager of Grassroots Advocacy and first registered federal lobbyist with Down syndrome, in her spoken comment to the Department during a recent listening session. A video of Ms. McKeon's comment can be found [here](#).

Section 504 has for decades played a critical role in protecting the rights of individuals with disabilities in programs and activities that receive federal financial assistance. Section 504 provides that "No otherwise qualified individual with a disability in the United States . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance," and, furthermore, the current Section 504 regulations require a local education agency (LEA) to provide a "free appropriate public education" (FAPE) to each qualified student with a disability who is in the LEA's jurisdiction, regardless of the nature or severity of the disability.

As a general matter, students with Down syndrome are often eligible for services under the Individuals with Disabilities Education Act (IDEA). In the field, there is some confusion among practitioners that students can be protected under one law or other – in reality, many are

covered by both 504 and IDEA. It is imperative, therefore, that the Department recognize and consider the unique needs of students who are dually eligible and Section 504 and ensure that practitioners understand those considerations.

In order to promote the best possible outcomes for students with Down syndrome and other disabilities qualified for the protections of Section 504, the National Down Syndrome Society recommends that the Department makes the following changes to the regulations: **modernize language to reflect a current understanding of disability rights; improve overall accessibility; and clarify and strengthen protections for students with disabilities in higher education.**

### **Recommendation 1: Update Outmoded Language.**

NDSS urges the Department to align definitions and language found in the Section 504 regulations to be consistent with language found in the Americans with Disabilities Act (ADA) (as amended) and the disability community's preferred language. More specifically, the use of the word "handicap" as it appears in §104.3 and throughout the regulations should be updated to "disability," with a definition of reflective of that in the Americans with Disabilities Amendments Act of 2008, which clarifies "disability" is meant to be constructed broadly in favor of expansive coverage, including a non-exhaustive list of major life activities.<sup>1</sup> This change would not only help ensure that federal language is consistent across various statutes and regulations, but it would also codify the preferred language used by many in the disability community.

Anecdotal evidence suggests that most individuals with Down syndrome prefer person-first language. Person-first language simply refers to the practice of referring to a person *first* and before their disability – in this case "person with Down syndrome."<sup>2</sup> In her testimony delivered to the Department via listening session, NDSS Manager of Grassroots Advocacy and prominent self-advocate Kayla McKeon put it best: "I am a woman with Down syndrome, but I am so much more. I am also a loving daughter, a loyal friend, a committed girlfriend, and a dedicated professional. I am NOT handicapped by my disability, and I strongly urge the Department to replace the use of the word "handicap" and other outdated language found in the current regulations."

Language is important. In particular, the operative language found in statute, regulation, and guidance has the power to shape the way society views people with disabilities. Antiquated language only serves to perpetuate anachronistic stereotypes of disability. The Department must do its part to reframe this deficit-based narrative by updating its language to reflect the many strengths and inherent value of students with disabilities.

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<sup>1</sup> See: Americans with Disabilities Amendments Act Regulations, (2008) at: [https://www.ada.gov/regs2016/final\\_rule\\_adaaa.html](https://www.ada.gov/regs2016/final_rule_adaaa.html)

<sup>2</sup> See: National Down Syndrome Society, Preferred Language Guide, (2022), at: <https://www.ndss.org/sites/default/files/pdf/2022-05/NDSS-Preferred-Language-Guide-2020-2.pdf>

## **Recommendation 2: Strengthen accessibility requirements related to all forms of technology, communication, and auxiliary aids and services.**

Students with Down syndrome have a unique learning profile, with their own unique cognitive and communication needs that must be accommodated – and strengths to be considered.<sup>3</sup> Notably, students with Down syndrome often experience hearing loss or impairment, verbal memory weakness, speech and language delay, visual learning strengths, and visual impairment, among other characteristics.<sup>4</sup> Many students with Down syndrome can benefit from the use of Assistive and Augmentative Communication (AAC) devices to support them in effective communication.<sup>5</sup>

For these reasons, it is crucial that the Department make clear the obligation of programs and activities that receive federal financial assistance to make all communication accessible to students with disabilities. Practices such as promoting the use of Universal Design for Learning (UDL)<sup>6</sup> and utilizing plain language in written communications,<sup>7</sup> allowing for the use of supplemental aids and supports for students with IDD, and ensuring that the use of AAC is accommodated as common practice.

NDSS further urges the Department to review the pre-existing body of guidance on accessible and effective communication and coordinate with other federal agencies to adopt regulations that lay out the highest level of accessibility reasonably possible. This review and coordination should include the Marrakesh Treaty Implementation Act (MTIA)<sup>8</sup> and its associated Senate report,<sup>9</sup> the 2014 joint guidance from ED and the Department of Justice (DOJ) on Effective Communication for Students with Hearing, Vision, or Speech Disabilities in Public Elementary and Secondary Schools,<sup>10</sup> and coordination as appropriate with the Department of Justice (DOJ) the Department of Health and Human Services (HHS), and other agencies.

## **Recommendation 3: Ensure and clarify existing protections for students with intellectual and developmental disabilities and students in inclusive postsecondary programs in higher education.**

Students with Down syndrome have long faced barriers to access and inclusion in higher education. In recent years, an increase in the number of Comprehensive Transition and

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<sup>3</sup> See: National Down Syndrome Society, Inclusive Education Guidelines, “The specific learning profile in more detail”, page 19, (2021), at: [https://www.ndss.org/sites/default/files/2022-06/2021\\_Inclusive\\_Education\\_Guidelines\\_v09%5B1%5D\\_0.pdf](https://www.ndss.org/sites/default/files/2022-06/2021_Inclusive_Education_Guidelines_v09%5B1%5D_0.pdf)

<sup>4</sup> See: APPGDS UK, Down Syndrome: Good Practice Guidelines for Education, (2012), at: <https://assets.cdn.down-syndrome.org/files/reports/appg-down-syndrome-education-guidelines-report-2012.pdf>

<sup>5</sup> See: National Down Syndrome Society, Inclusive Education Guidelines, “Augmented and Alternative Communication”, page 39, (2021), at: [https://www.ndss.org/sites/default/files/2022-06/2021\\_Inclusive\\_Education\\_Guidelines\\_v09%5B1%5D\\_0.pdf](https://www.ndss.org/sites/default/files/2022-06/2021_Inclusive_Education_Guidelines_v09%5B1%5D_0.pdf)

<sup>6</sup> See: CAST, UDL Guidelines, (2018), at: <https://udlguidelines.cast.org/>

<sup>7</sup> See: Plain Language Action and Information Network, at: <https://www.plainlanguage.gov/about/definitions/>

<sup>8</sup> See: United States Copyright Office, *Understanding the Marrakesh Treaty Implementation Act*, (2020), at [https://www.copyright.gov/legislation/2018\\_marrakesh\\_faqs.pdf](https://www.copyright.gov/legislation/2018_marrakesh_faqs.pdf)

<sup>9</sup> See: United States Senate, *Report on the Marrakesh Treaty Implementation Act*, (2018), at: <https://www.govinfo.gov/content/pkg/CRPT-115srpt261/html/CRPT-115srpt261.htm>

<sup>10</sup> See: U.S. Department of Justice, Civil Rights Division, and U.S. Department of Education, Office for Civil Rights and Office of Special Education and Rehabilitative Services, *Frequently Asked Questions on Effective Communication for Students with Hearing, Vision, or Speech Disabilities in Public Elementary and Secondary Schools*, (2014) at: <https://www2.ed.gov/about/offices/list/ocr/docs/dcl-faqs-effective-communication-201411.pdf>

Postsecondary Programs (CTPs)<sup>11</sup> has led to increases in enrollment of students with Down syndrome and other intellectual disabilities, but many structural impediments remain. As a result, students in these programs are often denied services under Section 504 due to their matriculation in non-degree-bearing programs. Because protections under IDEA do not extend to higher education, these postsecondary students are too often left without the services they need to reach their potential. The Department must clarify that students with intellectual disabilities in higher education, whether enrolled in degree-bearing or enrolled inclusive post-secondary programs, are qualified under Section 504 to receive the same aid, benefits, and services provided to other qualified students.

Furthermore, the Department should clarify that prior documentation of a disability, such as an Individualized Education Plan (IEP) that is legally mandated under IDEA, suffices as acceptable documentation to prove that the student is a person with a disability and therefore qualified to receive academic adjustments in higher education in accordance with Section 504. As it stands, students with disabilities are often required to “reprove” or redocument their disability through additional and oftentimes costly assessments and evaluations. This circumstance not only places undue stress and burden on students with disabilities and their caregivers, but, for students with Down syndrome in particular, re-evaluation is illogical and unnecessary since Down syndrome is typically diagnosed prenatally or at birth and is permanent.<sup>12</sup>

We are grateful to OCR and the Department for the opportunity to provide input during this public hearing. The National Down Syndrome Society is eager to work with the Department to promote positive education outcomes for everyone in the Down syndrome community. For further information regarding these comments, please do not hesitate to contact us at [education@ndss.org](mailto:education@ndss.org).

Sincerely,

A handwritten signature in black ink that reads "Kandi Pickard". The signature is written in a cursive, flowing style.

Kandi Pickard  
President and CEO  
National Down Syndrome Society

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<sup>11</sup> See: U.S. Department of Education, Transition and Postsecondary Programs for Students with Intellectual Disabilities, at: <https://www2.ed.gov/programs/tpsid/index.html>

<sup>12</sup> See: National Down Syndrome Society, “About Down Syndrome”, at: <https://www.ndss.org/about>