



Suzanne Goldberg
Acting Assistant Secretary for Civil Rights
U.S. Department of Education
Office for Civil Rights
400 Maryland Avenue, SW
Washington, DC 20202-1100

Dear Acting Assistant Secretary Goldberg:

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 Office for Civil Rights and the Department of Education's call to the public requesting information for the purpose of improving enforcement of Title IX of the Education Amendments of 1972. NDSS is grateful to the Department for taking the initiative to engage members of the community on this critical topic. In addition to regulatory comment, we are pleased to offer these written remarks. We also brought these listening sessions to the attention of a self-advocate on our staff who has elected to speak on her own behalf as a private citizen with Down syndrome, a young woman and a college student.

Sexual assault in schools, especially in higher education, has been a justifiable cause for alarm for students, the educators who teach them and the families who love them. For students with disabilities, the situation is only more dire: statistics show that individuals with intellectual and developmental disabilities are seven times more likely than their nondisabled peers to be sexually assaulted or raped and 12 times more likely if they are a female.¹ Youth with disabilities are almost twice as likely as their nondisabled peers to report coercive sex, forced sex and sexual abuse.² These statistics are even more unnerving when we take into account that incidents, overall, are often underreported.³

In the interest of promoting equity, the **National Down Syndrome Society recommends, in the strongest possible terms, that the Department examine how implementation of the existing Title IX regulations do – and do not – support students with Down syndrome and other disabilities,** including and especially those with the most significant support needs. The Department must take

¹Bureau of Justice Statistics, Crime Against Persons with Disabilities, 2009- 2015 Statistical Tables, (U.S. Department of Justice, 2017), <https://www.bjs.gov/content/pub/pdf/capd0913st.pdf>

² Levine, P., Marder, C., & Wagner, M. (2004). Services and Supports for Secondary School Students with Disabilities. A Special Topic Report of Findings from the National Longitudinal Transition Study-2 (NLTS2). Menlo Park, CA: SRI International.

³ Smith, S.G., Zhang, X., Basile, K.C., Merrick, M.T., Wang, J., Kresnow, M., Chen, J. (2018). The National Intimate Partner and Sexual Violence Survey (NISVS): 2015 Data Brief – Updated Release. Atlanta, GA: National Center for Injury Prevention and Control, Centers for Disease Control and Prevention.

immediate action to prevent discrimination against or disparate impact on this underserved population. Additionally, **we recommend that the Department develop and employ a holistic approach to reduce the incidence of sex discrimination and harassment, including prophylactic opportunities outside the legal scope of Title IX**, to promote the development of healthy relationship skills among our nation’s young people – including students with disabilities.

Recommendation 1: Make Title IX Processes More Accessible

When an incident of sex discrimination or harassment (including assault) has occurred on campus, an administrative process, meant to satisfy Title IX’s requirements, is set in motion and is framed by a few general phases, including complaint, investigation and resolution. In each phase and across the national body of different schools’ Title IX processes, systemic inaccessibility prevents students with disabilities from sharing the same protections as their nondisabled peers. Inaccessibility in its various forms not only creates barriers to proper enforcement of Title IX but also disincentivizes student utilization of and engagement with this critical safety net. NDSS urges the Department to improve accessibility of all Title IX processes in order to reduce the disparate impact on students with Down syndrome and other disabilities.

The complaint phase, in which an alleged violation of Title IX is reported, is inaccessible in many ways. For a complaint to be processed correctly, a complainant or reporter must be able to identify an incident, feel safe enough to report it, be able to communicate it effectively, know to whom it should be reported and finally that person (to whom it was reported) must know what do with the information to trigger a school response under Title IX. This process can be unduly burdensome to students because so much of the onus falls on complainants who may be in a heightened emotional state brought about by having recently witnessed – or directly experienced – sexual discrimination, harassment or assault. They may not know where to turn or what to say. They probably do not feel safe. It is very likely they never committed information about the Title IX process to memory – if they ever received that information in the first place. There may be a particular member of the school’s faculty or staff with whom they feel comfortable enough to report the incident, but it is highly unlikely that person has been trained in Title IX process. It is equally unlikely that the school’s trained Title IX coordinator is well-versed in evidence-based accommodation techniques related to various disabilities, including Down syndrome. The effect is that for a person with an intellectual or developmental disability – especially if that disability impacts communication – these barriers may prove insurmountable without school support, and the incident is likely to go unreported.

The investigation and resolution phases present similar issues. Inaccessibility in the adversarial, quasi-judicial proceedings employed by many schools to perform “fact-finding” does not accommodate students with disabilities, regardless of whether they are the complainants or the accused. Individuals with disabilities often require specific supports to enable them to participate fully in ordinary activities. By virtually any metric, a high-stakes Title IX investigation, including any sort of hearing, is an extraordinary event. Because these systems are not true judicial proceedings, however, they do not

require the litany of constitutional protections endemic to criminal or even civil procedure, despite being modeled on those adjudicative systems. Proceedings-driven confrontation between the complainant and accused are especially problematic and raise serious concerns about retraumatizing students. These proceedings are difficult for everyone, but for those students who might be denied the assistance of a needed advocate, interpreter or other form of aid, the situation can be truly unfair. Without appropriate accommodations, it is easy for those with intellectual or developmental disabilities to be unable to understand their rights fully, to say nothing of interpreting correctly the legalese presented in these circumstances both aloud and in print. Without accommodation, how can they represent their own interests effectively, whether they are appearing as a victim or an accused?

There are many ways the Department can work to mitigate these problems either in regulatory directive or sub-regulatory guidance: The Department can recommend the use of universal design in all Title IX information; it can promote collaboration between Title IX coordinators and disability offices to create personal supports, evergreen resources and personnel directories; it can require that Title IX responses utilize plain language and account for the use of assistive augmentative communication devices, interpreters, advocates and other supports throughout the process; and finally the Department can help schools promote a better understanding of Title IX processes among both students and staff, such as during orientation and through periodic training. Finally, the Department can establish clearer minimum standards and best practices for accessibility and work to ensure those are utilized more uniformly across the country. Critically, the Department can work proactively to ensure that all the requirements of Title IX are enforced in such a way that they do not produce a disparate impact on students with disabilities.

Recommendation 2: Develop a Holistic, Inclusive Approach to Reduce the Incidence of Sex Discrimination and Harassment

Young people learn about relationships in school. Some of that education takes place in curricular environments, but much of it takes place outside the classroom. Social-emotional learning is a critical piece of every student's educational experience; cultivating healthy relationship skills among our youth is a primary way for leaders in education to reduce or prevent the exact type of discrimination and harassment Title IX prohibits.

For students with disabilities to have the same social-emotional learning opportunities as their nondisabled peers, and for those students who do not have disabilities to learn naturally how to interact with those who do, all types of students must be together. Inclusion is especially important, and too often set aside, in extra-curricular and non-instructional environments. If different types of people are separated from each other in the foundational years, how can we expect them to interact properly with each other in adulthood? Promoting inclusive culture is an important piece of a proactive strategy to reduce discriminatory behavior.

Learning about physical and mental health is another important part of a well-rounded education and a cornerstone of the development of lifelong healthy habits and relationships. Students with disabilities are routinely left out of these classes and are also less likely to learn about sexuality from their parents⁴ and healthcare providers.⁵ The inclusion of students with Down syndrome and other disabilities in comprehensive health and sex education is an urgent matter because research shows that exclusion from these lessons and conversations is correlated with the disproportionate rates at which youth with disabilities are victims of sexual abuse.⁶

NDSS recommends that the Department issue guidance to help state and local education agencies provide students with Down syndrome and other disabilities a robust and inclusive health education program alongside their peers without disabilities. While we do not suggest the Department develop a standard nationwide curriculum, we do hope these guidelines would consider alignment with the National Sexuality Education Standards⁷ and that the content include comprehensive, developmentally appropriate and culturally responsive instruction related to sexual health and violence prevention, healthy relationships and, critically, that these guidelines be written with an eye for accessible implementation so that, with appropriate accommodations, all students are able to fully understand and engage with the material.

We thank the Department of Education 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 the Down syndrome community. For further information regarding these comments, please contact us at education@ndss.org.

Sincerely,

A handwritten signature in black ink that reads "Kandi Pickard". The signature is written in a cursive, flowing style with a large loop at the end of the last name.

Kandi Pickard
President and CEO, National Down Syndrome Society

⁴ Pownall, J. D., Jahoda, A., & Hastings, R. P. (2012). Sexuality and sex education of adolescents with intellectual disability: Mothers' attitudes, experiences, and support needs. *Intellectual and Developmental Disabilities, 50*, 140-154. doi: 10.1352/1934-9556-50.2.140.

⁵ Holmes, L. G., Himle, M. B., Sewell, K. K., Carbone, P. S., Strassberg, D. S., & Murphy, N. A. (2014). Addressing sexuality in youth with autism spectrum disorders: Current pediatric practices and barriers. *Journal of Developmental and Behavioral Pediatrics, 35*, 172-178. doi: 10.1097/DBP.0000000000000030.

⁶ Anna C. Treacy, Shanon S. Taylor & Tammy V. Abernathy (2018) Sexual Health Education for Individuals with Disabilities: A Call to Action, *American Journal of Sexuality Education, 13*:1, 65-93, DOI: 10.1080/15546128.2017.1399492

⁷ The National Sexuality Education Standards can be found at <https://siecus.org/resources/national-sexuality-education-standards/>