

Congress of the United States
Washington, DC 20515

July 25, 2023

The Honorable Katherine Neas

Assistant Secretary
Office of Special Education and Rehabilitative Services
United States Department of Education
400 Maryland Avenue, SW
Washington, D.C. 20202

RE: Guidance on affirming the eligibility of children with headache disorders under the IDEA Act

Dear Assistant Secretary Neas:

Millions of American children and adolescents experience disabling forms of migraine and headache disorders that can limit their performances in school. Despite the high prevalence and impact on school performance arising from migraine and other disabling headache disorders, they are inequitably not explicitly listed either among the qualifying diseases in section 1401(3)(A) of the Individuals with Disabilities Education Act (IDEA) statutes, or among the relevant regulations that implement these statutes. We respectfully ask the Department of Education to address this omission to ensure the educational success of countless children throughout the nation.

As it stands, the statutory and regulatory language is clear; the list is non-exhaustive and other conditions may qualify if they are chronic or acute and adversely impact a student's education performance. The omission from the statutory and regulatory language has created confusion amongst school districts, with some explicitly excluding children with disabling health impairments that impact their school performance from the special education services they need and deserve.

As such, we request the Office of Special Education and Rehabilitative Services issue a formal guidance memorandum affirming the potential eligibility of children with migraine and headache disorders under the "Other Health Impairments" category of the IDEA Act statutes should their health conditions adversely impact their educational performance in school.

The IDEA Act is a crucial group of statutes that provides equity in educational opportunities for children in public schools.^[1] This law ensures a "free appropriate public education in the least restrictive environment" for children with disabilities, including those who have a qualifying "other health impairment," as specified in the statute [section 1401(3)(A)], so long as the health

impairment of disability impacts their educational performance. Students who qualify under IDEA are accommodated through an individualized education plan (IEP).

The impact of headache disorders and migraine on children is significant. Migraine is the second leading cause of global disability.^[2] Millions of American children and adolescents experience disabling forms of migraine and headache disorders that can limit their performances in school.^[3] Migraine impairments are not limited to headache and pain; they may also arise routinely in children from sensory, severe light, noise, or odor sensitivity, mood, fatigue, equilibrium, nausea, vomiting, gastrointestinal, and / or autonomic symptoms. Significant cognitive impairments such as aphasia; where a loss of an ability to speak and understand language can occur, along with, brain fog, memory and attention deficits. Other possible and disabling symptoms include paralysis and a loss of motor control, as well as, vision impairment, including vision loss and double vision. Migraine attacks can begin at an early age and the prevalence increases with age, especially around the adolescent years.

Not all children with migraine or other headache disorders will need special education services. The disability impacts of migraine can vary with symptom frequency and severity, often with the most disabling form being chronic migraine, with 15 or more days with headache per month, again often accompanied by significant cognitive symptoms and other disabling symptoms. As many as 1 million children in our nation's Pre-K through Grade 12 public schools (1.7% of 49.4 million) may have chronic migraine, and who might therefore benefit from accommodations to be covered by the IDEA Act. The number of eligible children with headache disorders may be even higher when taking into account other primary and secondary headache disorders.^{[4][5]} School-aged children with these chronic headache conditions report "frequent school absences, poorer school performance, and lower quality of life than youth with other chronic conditions."^[6]
[7]

Despite the disabling nature of these conditions that can clearly impact a student's ability to learn, the omission of migraine and headache disorders from the list of qualifying conditions under IDEA Act statutes and regulations, leaves the eligibility of these children for special education services and IEPs open for interpretation by individual school districts. Children experiencing these painful, disruptive, disabling disorders have been excluded from coverage under IDEA by their school districts who simply do not fully appreciate what these conditions entail and how the frequently accompanying cognitive and other severe symptoms can impair a child's ability to learn. By way of example, a child with chronic migraine was denied special education services under IDEA by his Pennsylvania school district which asserted that while "*migraines constitute a health issue, they do not affect cognitive skills necessitating adaptation of the normal curriculum.*"^[8] Eligibility for an IEP for a student experiencing migraine or headache disorders should not be dependent upon that child happening to live within the boundaries of a sympathetic and understanding school district or judicial jurisdiction.

Addressing this issue with a guidance memorandum will have a positive impact on not just children with migraine and other headache disorders but also, other health conditions that are similarly excluded from IDEA statutory and regulatory language.

By issuing a formal guidance statement, the Department of Education can assist both children and school districts alike, by clarifying that the eligibility list under the “Other Health Impairments” category is non-exhaustive and that it is improper to deny special education services if a relevant condition is not explicitly listed. Instead, school districts have an obligation to look at the way in which a chronic or acute health condition, such as chronic migraine or other headache disorders, impact the child’s educational performance.

We are sensitive to and understand that IDEA remains critically underfunded and that there may be concerns with issuing this guidance and its potential impact on caseload. However, we maintain that issuing such guidance will not open the floodgates to these claims. The “such as” language of the regulations is already in effect, and therefore these children are already covered. This guidance memorandum will help ensure school districts better understand their obligations under IDEA, which can perhaps help avoid costly litigation for all parties and a delay in services for children who need them, as a result of an improper denial of special education eligibility for our most vulnerable children.

This guidance statement should bring us closer to ending the prevalent stigma around headache and migraine disorders and improve the educational prospects and future successes of impacted children around the country. We greatly appreciate your attention and thank you for considering this request.

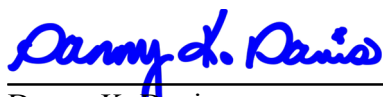
Sincerely,



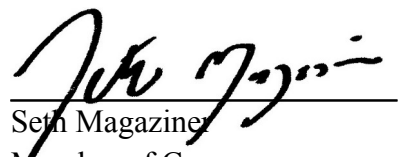
Cori Bush
Member of Congress



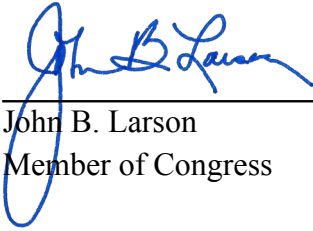
Dan Goldman
Member of Congress



Danny K. Davis
Member of Congress



Seth Magaziner
Member of Congress



John B. Larson
Member of Congress



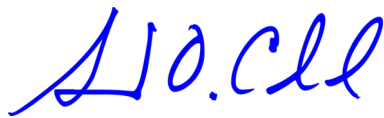
Ted W. Lieu
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Salud Carbajal
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Andy Kim
Member of Congress



Shri Thanedar
Member of Congress



Terri A. Sewell
Member of Congress

^[1] 20 USC Ch. 33: EDUCATION OF INDIVIDUALS WITH DISABILITIES

<http://uscode.house.gov/view.xhtml?path=/prelim@title20/chapter33&edition=prelim>

^[2] WHO Global Burden of Disease study; <http://ihmeuw.org/5pgh>

^[3] Youssef PE, Mack KJ. Episodic and chronic migraine in children. *Dev Med Child Neurol*, 2020;62:34-41. <https://doi.org/10.1111/dmcn.14338>

^[4] National Center for Education Statistics, Fast Facts, <https://nces.ed.gov/fastfacts/display.asp?id=372>

^[5] Ozge A, Ozgur Yahn O. Chronic migraine in children and adolescents. *Curr Pain Headache Rep* 2016;20:14. <https://link.springer.com/content/pdf/10.1007/s11916-016-0538-z.pdf>

^[6] Turner SB, Szperka CL, Hershey AD, Law EF, Palermo TM, Groenewald CB. Association of headache with school functioning among children and adolescents in the United States. *JAMA Pediatr.* 2021;175(5):522–524. doi:10.1001/jamapediatrics.2020.5680

^[7] Gu, L., Wang, Y. & Shu, H. Association between migraine and cognitive impairment. *J Headache Pain* **23**, 88 (2022). <https://doi.org/10.1186/s10194-022-01462-4>

^[8] S.P. v. Fairview Sch. Dist., Civil Action No. 13-96E (W.D. Pa. Sep. 30, 2014)