July 28, 2023

Rebecca Walawender
Director
U.S. Department of Education
400 Maryland Ave. SW, Room 5130
Potomac Center Plaza
Washington, DC 20202


Dear Director Walawender:

Founded in 1998, COPAA is an independent, nonprofit organization of over 3100+ parents, attorneys, advocates, and related professionals; over 90% of whom identify as having a disability or are parents or family members of individuals with disabilities. COPAA members nationwide work to protect student civil rights and secure excellence in education on behalf of the nearly 8 million students ages 0-21 with disabilities in America. COPAA members have lived experience with how the Individuals with Disabilities Education Act (IDEA), Section 504 of the Rehabilitation Act (504), the American with Disabilities Act (ADA) and countless Federal, state, and local laws and their regulations work to protect the rights and impact the educational access and experience of students with disabilities and their families. Our community members are active in all 50 states, the District of Columbia, and several US territories.

As the nation's leading authority on special education law, we are supporting parents and mentoring those who defend the educational rights of students with disabilities. Our members are also a proud part of the disability community. They are diverse, have lived experience with disabilities themselves, they have children and family members with a disability and/or they support clients with complex medical, educational, behavioral, and academic needs. To that end, we are pleased to provide recommendations to the U.S. Department of Education, Office of Special Education and Rehabilitative Services (OSERS) regarding the Notice of Proposed Rulemaking (NPRM) that seeks to amend Part B of the IDEA regulations to remove the requirement for public agencies to obtain parental consent prior to accessing for the first time a child’s public benefits or insurance (e.g., Medicaid, Children’s Health Insurance Program) to provide or pay for required IDEA Part B services.

COPAA’s recommendations to OSERS are:

1. **Listen to and take action to implement the recommendations made by the Consortium for Constituents with Disabilities (CCD):**
   - Maintain the current requirements at §300.154(d)(2)(iv) and §300.154(d)(2)(v) to retain the “first time” parental consent requirement and related statements;

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• Maintain the current requirement at §300.154(d)(2)(i) through (iii) to include written notification to parents the “no cost” provisions;
• Work directly with the Centers for Medicare and Medicaid Services (CMS) to improve state implementation of Medicaid for IDEA-eligible students; and,
• Make annual federal budget recommendations that would put IDEA Part B on a glide path to full funding such that schools would have the funds they need to deliver required IDEA services.

COPAA and CCD partners have worked vigorously to analyze OSERS proposal and assess the impact on children with disabilities and their families. While COPAA [and CCD] agree with the OSERS goal to assure school districts are compensated for school-based services, we believe the elimination of both the “first time” consent and the related statements places too many children at risk for not having access to needed services outside of school. Consistent with this concern, CCD has provided recommendations that OSERS can address by providing increased technical assistance to states and districts to improve transparency in the process to obtain the first time consent and related notifications that protect student privacy as well as civil rights while also helping schools obtain reimbursement when parents agree. CCD also makes recommendations for ways OSERS can work directly with the Centers for Medicare and Medicaid (CMS) to address critical implementation, communication, and billing issues [with state agencies] that have nothing to do with parental consent and everything to do with complex federal-state-local policies that only policy leaders can solve.

To this point, COPAA conducted a short, informal survey regarding the NPRM and received input from nearly half the states. Numerous members shared examples of the myriad of adverse ways removal of first time consent to bill Medicaid could have on parents seeking therapy or other related services outside of school because many state Medicaid plans currently consider this 'double dipping' and regularly deny services regardless of the child’s need. In particular, medically fragile children were consistently raised because a parent may need to have the ability to say ‘no’ to a district accessing Medicaid benefits due to visit limits the plan may place on a child's therapies. Given that these children may require multiple surgeries in a year followed by therapy or require therapies during specific times of year when the child is not in school, the flexibility is just not built into a system that allows the district to automatically bill. COPAA members also expressed significant concern with current district practices regarding Medicaid billing. The concerns range from deep mistrust of the district’s ability and intent to bill accurately to outright fraud where districts bill for services not provided (proved through district auditing). While the NPRM proposes that in lieu of parent first time consent that districts would be required to provide written notification to the parent prior to billing Medicaid, COPAA parents were adamant that such notification may not be timely (and would then have a direct negative impact on visit limits), may not reach them due to breakdowns in school-to-home communications, and/or may never be provided at all.

2. Work to assure districts provide IEP services, regardless of payor.

In light of what COPAA has shared above, we urge OSERS to work with states and districts to meet their obligations under IDEA and provide the services agreed to in a student’s IEP regardless of payor. COPAA members report that some schools and districts limit, reduce, or avoid providing services [as required on the IEP] when a parent refuses to consent to bill Medicaid. This is not in keeping with the requirements of IDEA and OSERS must clarify that regardless of payor, the district must provide any service agreed to in the IEP.
3. Do not assume that requirements under the Family Educational Rights and Privacy Act (FERPA) provide consent protections for IDEA-eligible children.

COPAA believes it would set a terrible precedent for OSERS to rely on FERPA requirements to also include first time consent to bill Medicaid as required by IDEA. FERPA establishes confidentiality and access rights for students’ educational records. Parents hold these rights until students turn 18 or enter postsecondary education.² As ED has noted, “…any disclosure of “education records” requires prior written consent of a parent or eligible student or must satisfy one of the exceptions to FERPA’s general consent requirement”³ and “the confidentiality of personally identifiable information (PII) in the education records of children with disabilities is further protected by Part B of the IDEA.”⁴ Neither FERPA nor IDEA’s privacy protections include the authority for a public agency to share information with Medicaid for billing purposes. As CCD noted, “FERPA and IDEA are not the same and the Department must not promulgate regulations that establish that they are. FERPA protects the sharing of personal student education records, which may/may not include medical or other information. IDEA’s requirement for parental consent to bill is just that.”⁵ While OSERS acknowledges, that [in the case of the NPRM moving forward] the protections under both FERPA and IDEA still apply⁶ and then indicates an “estimate” that “all 51 State educational agencies (SEAs) currently accessing Medicaid to pay for covered services [will] utilize a joint form for requesting FERPA and IDEA parent consent to disclose PII under Part B of IDEA (§ 300.622) and FERPA (§ 99.30)”⁷—assumedly for the purposes of billing Medicaid—COPAA believes both the proposal to eliminate a necessary consent and the assumptions herein are seriously flawed. Therefore, COPAA urges OSERS to reconsider the proposal.

COPAA appreciates the opportunity to comment and make important recommendations regarding the NPRM. Please let me know if we can provide additional information.

Sincerely,

Denise S. Marshall
CEO

www.copaa.org

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² 34 C.F.R., § 99.5.
⁵ See: CCD Letter to Walawender, August 1, 2023
⁷ Ibid. (page 31664).