



August 1, 2023

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

RE: Docket ID ED–2023–OSERS–0052: Assistance to States for the Education of Children with Disabilities

Dear Director Walawender:

The undersigned members of the Consortium for Constituents with Disabilities (CCD) appreciate the opportunity to provide comments on the Office of Special Education and Rehabilitative Services, Department of Education’s notice of proposed rulemaking (NPRM) to “amend the Individuals with Disabilities Education Act (IDEA) Part B 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 (CHIP)) to provide or pay for required IDEA Part B services.”

CCD is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration, and inclusion of children and adults with disabilities in all aspects of society free from racism, ableism, sexism, and xenophobia, as well as LGBTQ+-based discrimination and religious intolerance.

CCD appreciates that the proposed rule prioritizes ensuring IDEA-eligible students receive school-based services and attempts to increase funds for schools. While the intent of this proposed rule is honorable, we ask the Department to:

- 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;
- Maintain the current requirement at §300.154(d)(2)(i) through (iii) to include written notification to parents regarding 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.

## **Background**

As the NPRM references, there is a long and important history underscoring the value of parental consent. IDEA has made it clear through multiple iterations that parents and students should be at the heart of every decision throughout the IEP (Individualized Education Program) process. Parental consent is highlighted multiple times in both the statute<sup>1</sup> and regulations<sup>2 3</sup>. Consent is a bedrock principle to ensure the provision of civil rights, due process protections, and equitable provision of services.

When IDEA was reauthorized in 2004, it was followed by the Department's promulgated regulations in 2006 which accomplished several aims. These regulations helped align with the Family Educational Rights and Privacy Act (FERPA), created the "no cost" provisions at §300.154(d)(2)(i) through (iii) on which the Department currently seeks comment as part of this NPRM, and again, reemphasized the importance of parental consent. The Department struck the appropriate balance in 2013<sup>4</sup> when it revised the regulations from 2006 clarifying that the requirement for parental consent was required prior to accessing a child or parent's public benefits or insurance for the first-time, an annual written notification thereafter, and maintained the requirement to inform parents of the "no-cost" provisions. Thus, protecting a student's civil rights and ensuring that informed consent, understanding, and agreement for the billing of services was maintained.

As acknowledged in the NPRM, between 2013 and present day the Department has continued to receive feedback from certain stakeholders that this requirement for the first-time parental consent and annual written notification of intent to bill is simply too onerous a barrier for school districts as they seek to access public benefits and insurance to help fulfill their required duties to IDEA-eligible students. We would argue that a first-time parental consent is not a barrier, but rather is a powerful tool to ensure transparency between school districts and families and for parents to best assist their children as they receive health care services both within and outside schools to optimize their education. Critically, the NPRM cites no study or information to establish whether the first-time consent process is indeed too burdensome and confusing or if the parents are intentionally denying consent on the basis of their informed and deliberate choices.

### **Flawed Assumptions underpin the revision to the current consent process.**

Supporters of removing parental consent to bill Medicaid assume that parents are "confused" about what this form means for their child or "scared" to sign it and say that "chasing consents is a real problem and takes up many hours of non-reimbursable time"<sup>5</sup>. Even if some parents truly do not understand the form, many parents actually withhold consent to bill Medicaid for entirely valid and substantiated reasons.

The survey<sup>6</sup> conducted by proponents of removing first-time consent cites many of the important reasons why parents choose to withhold consent, including the reality that billing within schools can have a negative impact on services outside of the schools, and consent to bill services can result in undesired health information-sharing with the Local Education Agency (LEA), the Medicaid agency, and/or Medicaid Managed Care Organization (MCO).

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<sup>1</sup> Individuals with Disabilities Education Improvement Act of 2004, Section 615(d)(2)(B). Retrieved from <E:\PUBLAW\PUBL446.108>

<sup>2</sup> Federal Register / Vol. 71, No. 156 / Monday, August 14, 2006 / Rules and Regulations. Retrieved from <06-6656.pdf>

<sup>3</sup> Federal Register / Vol. 78, No. 31 / Thursday, February 14, 2013 / Rules and Regulations. Retrieved from [20130214-Part\\_B-final\\_regulations.pdf](20130214-Part_B-final_regulations.pdf)

<sup>4</sup> Federal Register / Vol. 78, No. 31 / Thursday, February 14, 2013 / Rules and Regulations, page 10525. Retrieved from [20130214-Part\\_B-final\\_regulations.pdf](20130214-Part_B-final_regulations.pdf).

<sup>5</sup> The School Superintendents Association et. al. (2023). Obtaining Parental Consent to Bill Medicaid. Retrieved from <https://www.aasa.org>

<sup>6</sup> The School Superintendents Association et. al. (2023). Obtaining Parental Consent to Bill Medicaid. Retrieved from <https://www.aasa.org>

*Parents withhold consent because services offered outside the schools are directly affected by school-based billing.*

There are scores of examples from CCD members and many already submitted by affected parents through this NPRM's request for public comment, that show billing Medicaid within the schools can harm the child receiving comprehensive healthcare in and outside the school. For example, CCD members report the following:

- CA: "MediCal will not provide private services (outside of the school day) to Medicaid-eligible children with disabilities if they pay the school districts for services." (advocate)
- IL: "Even with the "no cost" provision, families are sometimes told that a school service is duplicative of an identical out-of-school service." (advocate)
- TX: "For our family, it would be detrimental. We have a grandfathered private, non-employer based, health insurance policy with limitations for OT (Occupational Therapy), PT (Physical Therapy) and ST (Speech Therapy). Were we required to allow the school district to access our son's Medicaid Waiver, we would have to give up the necessary and limited OT, PT and ST that he can access during the summer months and after school before qualifying for anything at school. Our private health insurance is the primary payor before Medicaid reimbursement may be obtained. This would also impact access to and possibly eliminate needed outside [of school] therapy services that are necessary to meet the student's functional needs or to rehabilitate from injury or surgery. (parent)
- VA: "It harms my family due to a health plan with number of visit limits. I would not be able to preserve those visits for additional private services." (parent)

Parents are routinely informed, sometimes even after services in other settings have already been rendered, that the Medicaid agency has deemed them duplicative with school-based services and their coverage is denied. Children receiving extensive services outside of the school often lose this coverage due to the Medicaid agency or MCO determining that they have received those services on the same day or even just because they are the same type of provider offering them. Despite the existence of the "no cost" guardrails at §300.154(d)(2)(i) through (iii) already in place to prevent this type of scenario from occurring, in the situations where parents *have* given consent, MCOs and/or the state Medicaid agency routinely ignore the requirement to cover services in other settings for Medicaid-enrolled kids whose healthcare services are billed to Medicaid in the school setting. CCD recognizes that these issues should not occur under current law and there are significant and problematic implementation problems with the 3<sup>rd</sup> Party billing process. However, CCD asserts that these implementation issues should be addressed before the Department changes the parent consent regulations in 300.154 and that parents should not bear the brunt of school district and/or state Medicaid agency problems.

If parents lose the ability to consent for Medicaid to be billed in the school, parents lose the ability to opt out of such billing if the school is not the best setting for services for their child for any number of reasons, including differences in the kind of services frequently offered in school (e.g., group versus individual therapy); the length of service session (e.g., meeting a need for longer or more frequent sessions outside of school); and free choice of provider (e.g., having a previous preferred therapeutic relationship with a provider outside of the school), and others. Allowing a school district to unilaterally have the authority to elect for school-based services to be billed *without the full knowledge of the child's complementary needs outside of a school setting* will have a negative impact on a child's ability to receive the highest quality comprehensive services. CCD addresses the Department's proposal to include FERPA consent to disclose personally identifiable information (PII) with consent to bill Medicaid below.

Supporters of removing IDEA's first-time consent requirement along with requirement to provide the statements required by 300.154(d)(2)(v) would say that the issues raised here exist even with parental consent in place, thus their removal would not cause more harm. CCD disagrees. Maintaining first-time parental consent provides an important opportunity for parents to remain active participants in determining the best setting for children to receive services and the statements ensure they understand a) their right to withdraw consent to disclose their child's PII; and b) that removal of consent does not relieve the school district of its obligation to provide IDEA-services. If parents lose the opportunity to affirmatively consent, these problems could be absolutely intensified if services for children who had previously not been billed to Medicaid now face the same coverage challenges across settings. Proponents also argue that even with the proposed changes, parents still can opt out. We would argue that moving to a notification system that also removes the distinct requirement to notify parents of their right to opt-out, instead of one of consent to billing combined with a statement of their ability to optout, precludes most parents from having the knowledge that they can opt out unless the school district decides to specifically communicate this option. However, the proposed regulations do not require that specificity in the notification process.

*Parents withhold consent because they do not wish to share all their child's personal information with the LEA, MCO, or Medicaid state agency.*

We appreciate that the requirements under FERPA regarding disclosure and parental consent for evaluation and services under IDEA are maintained with this rule. Indeed, these privacy guardrails are applicable to and essential in the school setting. FERPA is a separate law from IDEA and as such FERPA's consent process remains secondary and indirectly related to IDEA's notice and process provisions. In other words, 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.

CCD believes that removing IDEA's requirement for parental consent for school districts to bill Medicaid for services will have a negative impact on the provision of health care services beyond the IEP construct. Indeed, this proposed rule would allow the school district to make decisions regarding how a student's most personal health care records are shared with educational agencies and their personnel (contract and non-contract) that a parent and/or student may not want to share. We think specifically of mental health services where children may not want to discuss their family mental health issues in a group or school setting. In schools, it is not uncommon for word to travel fast if a student needs support for an array of health services. Some students may not wish others at school to know they need certain health services, and they should retain that right.

Alternatively, some parents may not wish the Medicaid agency to have a copy of their child's IEP. We have heard from parents that their child's providers who work in the outpatient setting are routinely asked by Medicaid state agencies or MCOs for a copy of the child's IEP, which is then used to deny coverage for services because of the assumption they are duplicative. The IEP can contain very personal details about a student that the Medicaid agency or MCO simply do not need to know.

Such decisions regarding the location of Medicaid provided services are best left to the parent and student. They are the only individuals that have a comprehensive understanding of the impact of sharing personal information with other agencies and individuals. As more data, even meta data is shared, it increases the chances of an unauthorized disclosure of a student's most personal health care information.

**The types of Parental Consent in the IEP process are not fungible.**

While we understand that there are other components of parental consent involved in IDEA, they are different in kind than that of the current version of parental consent to bill Medicaid. For instance, under Section 615(d)(2) procedural safeguards, prior written notice<sup>7</sup>, parental consent<sup>8</sup>, and access to educational records<sup>9</sup> are listed separately.

As noted, FERPA is primarily about consent for the disclosure of personally identifiable information as it pertains to educational records. FERPA does not primarily speak to consent for matters pertaining to accessing IEP services or understanding and agreeing to billing for services such as Medicaid and the impact of such consent on the ability of a child to access future non-IDEA Medicaid health care services. Consent for the disclosure of information is different than consent for evaluation or services. This is part of the reason the requirements of FERPA are different than the consent for a child to be evaluated for IDEA eligibility per 34 CFR 300.300(a)<sup>10</sup> and consent for a child to receive education services under IDEA per 34 CFR 300.300(b)<sup>11</sup>.

Furthermore, the consent for Medicaid approved providers to bill for IEP services per 34 CFR 300.154(d)(2)(iv)<sup>12 13</sup> is a guardrail to help ensure the provisions of Section 640(c) are followed to the maximum extent practicable that “Nothing in this part shall be construed to permit the State to reduce medical or other assistance available or to alter eligibility under title V of the Social Security Act (relating to maternal and child health) or title XIX of the Social Security Act (relating to Medicaid for infants or toddlers with disabilities) within the State”<sup>14</sup>.

While there is some overlap, each consent provision provides a unique and materially different statutorily based safeguard to ensure the maximum provision of services without incurring unintended harm to the child. We suggest maintaining the current language that “specifies that the parent understands and agrees that the public agency may access the parent’s or child’s public benefits or insurance to pay for services under part 300.”<sup>15</sup> This current requirement is a key safeguard to help ensure that IEP services cannot diminish other Medicaid-reimbursable services and that services are delivered at no cost to the child’s family.

In addition to the three types of consent listed above, in the regulatory discussions the Department made the distinction between the concepts of ‘consent’ and ‘agree’. In the past, the Department specifically has said that “the meaning of the terms ‘agree’ or ‘agreement’ is not the same as ‘consent.’”<sup>16</sup> The regulatory discussion further clarified the distinction between ‘agree’ and ‘consent.’ The proposed changes to 300.154(d)(2)(iv)(B)<sup>17</sup> specifically remove the understands and agree standard in addition to ‘consent.’ While there is some overlap, these consent provisions are distinct concepts based on the

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<sup>7</sup> Individuals with Disabilities Education Improvement Act of 2004, Section 615(d)(2)(B). Retrieved from [E:\PUBLAW\PUBL446.108 \(congress.gov\)](E:\PUBLAW\PUBL446.108 (congress.gov))

<sup>8</sup> Individuals with Disabilities Education Improvement Act of 2004, Section 615(d)(2)(B). Retrieved from [E:\PUBLAW\PUBL446.108 \(congress.gov\)](E:\PUBLAW\PUBL446.108 (congress.gov))

<sup>9</sup> Individuals with Disabilities Education Improvement Act of 2004, Section 615(d)(2)(B). Retrieved from [E:\PUBLAW\PUBL446.108 \(congress.gov\)](E:\PUBLAW\PUBL446.108 (congress.gov))

<sup>10</sup> Code of Federal Regulations, 34 CFR 300.300(a). Retrieved from [https://www.ecfr.gov/current/title-34/subtitle-B/chapter-III/part-300/subpart-D/subject-group-ECFR0e487e9b8f716c0/section-300.300#p-300.300\(a\)](https://www.ecfr.gov/current/title-34/subtitle-B/chapter-III/part-300/subpart-D/subject-group-ECFR0e487e9b8f716c0/section-300.300#p-300.300(a))

<sup>11</sup> Code of Federal Regulations, 34 CFR 300.300(b). Retrieved from [https://www.ecfr.gov/current/title-34/subtitle-B/chapter-III/part-300/subpart-D/subject-group-ECFR0e487e9b8f716c0/section-300.300#p-300.300\(b\)](https://www.ecfr.gov/current/title-34/subtitle-B/chapter-III/part-300/subpart-D/subject-group-ECFR0e487e9b8f716c0/section-300.300#p-300.300(b))

<sup>12</sup> U.S. Department of Education. Methods of Ensuring Services 300.154. Retrieved from <Sec. 300.154 Methods of ensuring services - Individuals with Disabilities Education Act>

<sup>13</sup> Posny, A. (2007, May 3). United States Office of Special Education Programs. Interpretation of 34 CFR §300.154(d)(2)(iv)(A). Retrieved from [OSEP Memo 07-10 Interpretation of 34 CFR §300.154\(d\)\(2\)\(iv\)\(A\) \(ed.gov\)](OSEP Memo 07-10 Interpretation of 34 CFR §300.154(d)(2)(iv)(A) (ed.gov))

<sup>14</sup> Individuals with Disabilities Education Improvement Act of 2004, Section 640(c). Retrieved from [E:\PUBLAW\PUBL446.108 \(congress.gov\)](E:\PUBLAW\PUBL446.108 (congress.gov))

<sup>15</sup> U.S. Department of Education. Methods of Ensuring Services 300.154. Retrieved from <Sec. 300.154 Methods of ensuring services - Individuals with Disabilities Education Act>

<sup>16</sup> Federal Register / Vol. 71, No. 156 / Monday, August 14, 2006 / Rules and Regulations Page 46629. Retrieved from [06-6656.pdf \(govinfo.gov\)](06-6656.pdf (govinfo.gov))

<sup>17</sup> U.S. Department of Education. Methods of Ensuring Services 300.154. Retrieved from <Sec. 300.154 Methods of ensuring services - Individuals with Disabilities Education Act>

Department's historic interpretation outlined in part in the previous regulatory discussion of these issues and the statutory provisions outlined by Congress. We recommend that all three types of consent continue to be required because each has and serves a distinct purpose.

**Removing Parental Consent creates inequities and exacerbates existing problems with accessing services for Medicaid.**

The proposed rule emphasizes that removing the requirement for parental consent to bill Medicaid will ensure equal treatment of Medicaid-eligible children with disabilities and Medicaid-eligible children without disabilities because the latter group does not require parental consent to bill Medicaid. First, parental consent to bill Medicaid is a best practice that should be afforded to both children with disabilities and those without. An example of where consent for a Medicaid-eligible child without an IEP would offer a benefit would be a child who does not have an IEP in school but needs mental health services as they relate to peer interactions in class. That child's parents would be best suited to determine whether the child should get services within the school or seek services from a different provider with specialty in navigating friend and peer relationships in the outpatient setting. The school provider may not have the schedule availability for the sessions needed by the student, may not have the expertise (as all mental health providers are not fungible), may only offer group therapy which may not be the best fit for the child, may not have a previously established therapeutic relationship like the student may have with an external provider, or other limitations.

If these proposed changes are implemented, Medicaid-eligible children with an IEP would have increased likelihood of coverage challenges over their peers who are Medicaid enrolled without an IEP. Medicaid eligible children who receive services in both school and other settings would be potentially subject to even greater difficulties than those of their peers with private insurance who can seek care outside the schools without the need to coordinate care between settings at all.

Medicaid eligible children are already subject to difficulties in obtaining healthcare services<sup>18</sup>. Fewer providers accept Medicaid for insurance for a host of reasons, including the incredible administrative problems associated with it<sup>19</sup>. We have heard complaints of non-compliance in North Carolina whereby budget limits and caps on services based on the number of hours for medically needy children, including those with autism are used to deny services, however, Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) protections are supposed to apply. This waiver would be extremely problematic for a family who could no longer opt out of billing Medicaid in the schools - they would be forced to receive services in the schools to avoid exceeding the cap on the number of service hours afforded to their child through the Medicaid waiver. In a health system that has the coverage guardrails that the EPSDT benefit afford (e.g. no caps on services provided)<sup>20</sup>, there are still ways that Medicaid enrolled children are denied coverage for healthcare services in ways not applied to other children.

To receive services, children with disabilities should not have to provide personal data that is beyond what a Medicaid eligible child without a disability would have to provide. To achieve equity, IDEA provides equitable support for the provision of Free Appropriate Public Education (FAPE). Children with disabilities need to be seen to receive the support they need regardless of the type of health insurance they have.

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<sup>18</sup> Hsiang WR, Lukasiewicz A, Gentry M, Kim CY, Leslie MP, Pelker R, Forman HP, Wiznia DH. (2019) Medicaid Patients Have Greater Difficulty Scheduling Health Care Appointments Compared With Private Insurance Patients: A Meta-Analysis. *Inquiry*. Retrieved from [doi: 10.1177/0046958019838118](https://doi.org/10.1177/0046958019838118). PMID: 30947608; PMCID: PMC6452575

<sup>19</sup> Scott, D. (2021). Medicaid is a hassle for doctors. That's hurting Patients. *Vox*. Retrieved from <https://www.vox.com/2021/6/7/22522479/mcicaid-health-insurance-doctors-billing-research>

<sup>20</sup> Medicaid and CHIP Payment and Access Commission. EPSDT in Medicaid. Retrieved from <https://www.macpac.gov/subtopic/epsdt-in-mcicaid/>

**Removing Parental Consent does not solve the funding problems it is attempting to solve.**

Supporters of removing parental consent to bill Medicaid state that districts will be much better situated to provide IDEA services when they can bill Medicaid freely for every eligible child, and no longer have to go through the extra steps of ensuring that a parent consents to services for their own child being billed to their health insurance. During a stakeholder webinar between the Centers for Medicare and Medicaid Services (CMS) and the Department of Education regarding this NPRM and the new Medicaid claiming guide for the schools, CMS staff publicly stated that they cannot compel state Medicaid agencies to ensure that the funds generated by schools billing Medicaid will return to them. They “encourage” agencies to do so, but ultimately rely on agencies and sometimes school districts to make sure the dollars generated become dollars received.

This CMS encouragement is simply not a strong enough incentive for agencies to direct funding to schools. In an earlier version of a similar survey of school superintendents conducted in 2017, less than half of respondents said that they used Medicaid funds to expand health related services for students<sup>21</sup>. While we know that reimbursement from Medicaid-billed services could potentially support IDEA services and does in certain districts, it is far from guaranteed. We know from both that same survey and many of our constituent provider groups that dollars generated in schools often do not return to the schools that generated them. Without legal obligation from the Medicaid agencies overseen by CMS, there is no guarantee that those funds will go on to support students receiving the services to which they are entitled, regardless of which health insurance they have. Thus, it is imperative that the Department work directly with CMS to address the known and ongoing problems which plague districts from receiving reimbursements via Medicaid. Removing consent from parents is not the appropriate fix to addressing these problems.

CCD, along with almost every other heavily invested education and healthcare advocacy organization, acknowledges that public schools and IDEA have been underfunded for a very long time. While Medicaid funding can be a helpful source for supporting schools, ultimately it is a bonus, and not the main source of funding. The Department’s focus should be on ensuring the full funding of IDEA. Siphoning limited funds from Medicaid to fund the civil rights obligations afforded under IDEA is an untenable solution. Children need robust funding in both educational and non-educational settings. There is already not enough funding for children in the health care space and it seems less than optimal to incentivize taking more money away from one source of revenue as opposed to ensuring that there is a glide-path to fully fund IDEA first. It is impossible for Medicaid to be a workaround for a lack of federal funding for essential programs, especially when getting the funds from Medicaid affords even less likelihood that those funds will be used for IDEA-eligible students.

It is also important to consider that each Medicaid program has a finite budget in every state. Given that fact, the idea that funding increased services in schools by eliminating the parental consent requirement will not affect payment for services outside of the schools is simply fiscally impossible. State Medicaid programs are losing more money every quarter as they incrementally lose the 6.2% federal matching boost they had during the pandemic.<sup>22</sup> 21.2 million people joined the Medicaid program between February 2020 and December 2022, and while some of these people are now being removed since the continuous enrollment requirement has expired, the program remains one of the largest health insurance programs for children available. Suggesting that increasing the number of services billed to Medicaid by

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<sup>21</sup> Pudelski, S. (2017). Cutting Medicaid: A Prescription to Hurt the Neediest Kids. AASA, *The School Superintendent's Association*. Retrieved from <https://eric.ed.gov/?id=ED601997>

<sup>22</sup> Medicaid.gov. *Unwinding and Returning to Regular Operations after COVID-19*. Retrieved from <https://www.medicaid.gov/resources-for-states/coronavirus-disease-2019-covid-19/unwinding-and-returning-regular-operations-after-covid-19/index.html>

removing parental consent will not affect funding for the same level of services outside the school does not comport with the difficult fiscal reality many state Medicaid programs are facing.

Some stakeholders view these coverage challenges outside the schools as merely an issue of MCO program administration or faulty implementation of IDEA requirements, instead of an issue of preserving parental consent for a variety of reasons, including to ensure children have access to the comprehensive services they need in and outside of the schools. As shown above with examples of state Medicaid program and MCO billing and coverage errors regarding alleged duplication of services, difficulties with program administration are not in question. The point remains that parents should be able to determine the best setting for services in response to an admittedly imperfect program administration across states.

The Department recently announced that most states fell short of their basic civil rights obligations to provide FAPE.<sup>23</sup> Given the known realities of state and district noncompliance with IDEA, combined with the \$22 billion shortfall in IDEA Part B funding that states and districts currently offset, CCD urges the Department to focus on IDEA compliance and make a budget recommendation that would put IDEA on a glide path to full funding thus working to ensure the current requirements of IDEA are met before making changes to IDEA that could have negative consequences for a child's ability to access vital IDEA services regardless of setting.

### **Recommendations and Suggestions for Improving the Current Regulations**

1. *Retain the First-Times Consent to Bill Medicaid, Related Statements and Annual No-Cost Notification Requirements:* The Department should maintain the current regulation and the related statements at 300.154(d)(2)(v) because the three types of consent are necessary and distinct. If implemented as required and in a timely manner, this creates transparency in the process for both parties, protects student civil rights, and ensures that informed consent, understanding, and agreement for services is maintained.
2. *Plain Language:* CCD has long understood the value of writing statements in plain language for all people, including those with disabilities<sup>24</sup>. We recommend that all three forms of parental consent described above be written in plain language to explain the distinct purposes of each. A person can face one or many different barriers to reading and/or understanding written or spoken language, including but not limited to: lack of access to an equal education; having one or more cognitive, communication, learning, mental, physical, sensory, or other disabilities; having a primary language other than English; multiple and intersecting forms of prejudice and discrimination; and societal inequalities perpetuated by racism, ableism, and other oppressions. While using plain language will not eliminate all the information barriers millions face, it is a major step in the right direction.
3. *The Department should work closely with CMS.* We recommend that the Department continue to work closely with CMS to address the coverage issues we have raised. The Department needs to actively work to ensure that dollars generated by school districts return via reimbursement to them. Whether that is through changing IDEA, encouraging CMS to change their own regulations, or some other pathway. Regardless, the Department must convey a stronger message that billable Medicaid funds must be used for IDEA-specific services.

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<sup>23</sup> Diament, M. (2023). Most States Fall Short in Special Ed, Feds Say. *DisabilityScoop*. Retrieved from <https://www.disabilityscoop.com/2023/07/10/most-states-fall-short-in-special-ed-feds-say/30447>

<sup>24</sup> Consortium for Constituents with Disabilities (2021). Retrieved from [https://www.c-c-d.org/Policies/CCD\\_Plain\\_Language\\_Policy.pdf](https://www.c-c-d.org/Policies/CCD_Plain_Language_Policy.pdf)



The recently released CMS Claiming Guide<sup>25</sup> cites the Free Choice of Provider Provisions<sup>26</sup> stating, “Thus, it is still the case that, as CMS stated in its 1997 guidance, States cannot limit Medicaid-eligible children to school health providers for Medicaid covered services.” If this were happening, none of the previously described issues regarding coverage of services simultaneously billed to Medicaid by providers in the school and providers outside the school would be occurring because beneficiaries could seek care from whichever provider they chose. Instead, children/families are only having Medicaid billing challenges with providers outside the school, violating the Free Choice of Provider provisions as they stand.

4. *Due Process*: We recommend that the Department provide clarity on due process procedures when services are denied outside of the schools based on those offered within them. We recommend that the Department require that these processes should be detailed in the consent to bill forms. Parents need to know that if they provide consent for the in-school service and they are getting a non-duplicative out-of-school service, that the Medicaid agency or MCO has no right to cut or deny that out-of-school service. Parents must have the right to appeal the cut to benefits and to receive continuing services while the appeal is being adjudicated (aid paid pending) so long as they appeal within 10 days.
5. *Further Elaborate No Cost Provisions*: Parents should be informed that, while not allowed, cuts to Medicaid services because of school-based billing is something that happens regularly. While the “no cost” provisions are helpful in theory, schools cannot guarantee that accessing a student’s public benefits will not cause issues for the student accessing out-of-school benefits in the future. We recommend that the federal rule, including the “no cost” provisions,” must require schools to provide information to parents regarding what specific benefits have been accessed by the school. We recommend adding to the “no cost” provisions a requirement that schools have the responsibility to ensure that parents do not incur any costs as the school bills for services and that no negative impact on lifetime coverage or access to services outside of school exist.
6. *Reporting Requirements*: Additionally, we propose the addition of a requirement that LEAs that accessed public benefits must provide an explanation of benefits annually to parents so that they are aware of what benefits were accessed and in what amount. This would help act as a guardrail on any potential billing fraud to the publicly funded Medicaid program. This concept can be accomplished with the addition of two new statements in a new subsection (d)(2)(v)(E) and (F). Paragraph E would be the prospective information statement for parents, and paragraph F would be the retrospective information statement for parents.
7. *Transferring Consent to alternative location*: If the Department continues to move forward with the current proposed changes despite the serious issues discussed above, the Department must detail how parents can prevent Medicaid billing of services via the FERPA notice. It is essential that parents retain the annual right to opt out of school-based Medicaid billing for their child.

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<sup>25</sup> The Centers for Medicare and Medicaid Services (2023). Delivering Services in School-Based Settings: A Comprehensive Guide to Medicaid Services and Administrative Claiming. Retrieved from <https://www.medicaid.gov/medicaid/financial-management/downloads/sbs-guide-medicaid-services-administrative-claiming.pdf>

<sup>26</sup> Code of Federal Regulations, 42 CFR 431.51 Free Choice of Providers. Retrieved from <https://www.ecfr.gov/current/title-42/chapter-IV/subchapter-C/part-431/subpart-B/section-431.51>

## Conclusion

Thank you for the opportunity to provide comments. This proposed rule attempts to fix a funding problem with noble intent. Ultimately, however, stripping parents of their rights to affirmatively consent for billing Medicaid for services for their IDEA-eligible child is not the solution. We believe our suggestions will help children with disabilities receive the best possible services across healthcare delivery settings and enable their parents to remain active stakeholders in the healthcare services they receive.

If you have any questions or need any further information, please contact Caroline Bergner ([cbergner@asha.org](mailto:cbergner@asha.org)) or Laura Kaloi ([lkaloi@stridepolicy.com](mailto:lkaloi@stridepolicy.com)).

Sincerely,

Access Ready

American Association on Health and Disability

American Speech-Language-Hearing Association

Association of Assistive Technology Act Programs

Autism Society of America

Autistic People of Color Fund (APOC)

Autistic Self Advocacy Network

Caring Across Generations

Center for Learner Equity

Children and Adults with Attention-Deficit/Hyperactivity Disorder

Council for Learning Disabilities

Council of Parent Attorneys and Advocates (COPAA)

Council of State Administrators of Vocational Rehabilitation (CSAVR)

Disability Rights Education & Defense Fund

Epilepsy Foundation

Family Voices

Lakeshore Foundation

Learning Disabilities Association of America

Muscular Dystrophy Association

National Association of Councils on Developmental Disabilities

National Center for Parent Leadership, Advocacy, & Community Empowerment (National PLACE)

National Disability Rights Network (NDRN)

National Down Syndrome Congress

The Advocacy Institute

Tourette Association of America

United Spinal Association