



OUR MISSION:

To advance access to the gift of hearing provided by cochlear implantation through research, advocacy and awareness.

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VIA Electronic Submission: Lisa.Pagano@Ed.Gov

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Washington, D.C. 20202

RE: Policy Interpretation Request of Part B and Part C of the Individuals with Disabilities Education Act

The American Cochlear Implant Alliance (ACI Alliance) is writing to request a policy interpretation by the Department of Education (the Department) of the applicable regulatory requirements of part B and part C of the Individuals with Disabilities Education Act (IDEA)¹ in the context of specific facts regarding the administration of the early intervention and special education programs administered by the Utah School for the Deaf and the Blind (USDB).

ACI Alliance is a non-profit 501(c)(3) organization whose membership includes parents, individuals with hearing impairments, clinicians, and researchers. Our mission is to advance the gift of hearing provided by cochlear implantation (CI) and other implantable prosthetic hearing technology through research, advocacy and awareness. Our mission is also to ensure that parents have early access to accurate and comprehensive information to facilitate fully informed participation in decisions impacting their children to support whatever choices the IFSP and IEP team makes on behalf of the child.

I. Applicable Statutory and Regulatory Requirements

Set out below is a summary of applicable IDEA statutory and regulatory requirements applicable to infants and toddlers with disabilities and children with disabilities.

¹ 20 U.S.C. §§ 1406(d)-(f); 34 CFR part 300 and part 303.

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Part C of IDEA assists states in operating a comprehensive statewide program of early intervention services for infants and toddlers with disabilities, ages birth to 3 years, as well as their families.² Once an infant or toddler is determined to be eligible for the early intervention program, an Individualized Family Service Plan (IFSP) is created to document and guide the early intervention process for children with disabilities and their families.³ A key part of the IFSP is to provide early intervention services that assist with the infant or toddler's communication development.⁴

Part C of the IDEA defines early intervention services as “developmental services that ... [a]re selected in collaboration with the parents” and are “designed to meet the developmental needs of an infant or toddler with a disability and the needs of the family to assist appropriately in the infant's or toddler's development, as identified by the IFSP team.”⁵ Early intervention services also include providing families with special instructions, including “information, skills and *support* related to enhancing the skill development of the child.”⁶

Part B of IDEA defines special education as “specially designed instruction...to meet the *unique needs* of a child with a disability.”⁷ Specially designed instruction means “adapting...the content, methodology, or delivery of instruction ... to address the *unique needs of the child*.”⁸ In designing the IEP for the child, the IEP Team must consider, among other things,

- The strengths of the child,
- The concerns of the parents for enhancing the education of their child,
- The results of the initial evaluation, and
- The academic, developmental, and functional *needs of the child*.⁹

The IDEA, as amended in 1997, also requires that the IEP Team consider the communication needs of the child (special factors) and in the case of a child who is deaf or hard of hearing, consider the:

- Child's language and communication needs,
- Opportunities for direct communications with peers and professional personnel in the child's language and communication mode,
- Academic level, and
- Full range of needs, including opportunities for direct instruction in the child's language and communication mode.¹⁰

² 34 C.F.R. § 303.1.

³ *Id.* § 303.321.

⁴ *Id.* § 303.13(a)(4)(iii); *see also Id.* § 303.21(a)(1)(iii).

⁵ *Id.* § 303.13(a).

⁶ *Id.* § 303.13(b)(14)(iii) (emphasis added).

⁷ *Id.* § 300.39(a)(1) (emphasis added).

⁸ *Id.* § 300.39(b)(3) (emphasis added).

⁹ *Id.* § 300.324 (emphasis added).

¹⁰ *Id.* § 300.324(a)(2)(iv).

Previously in 1992, the Office of Civil Rights and the Office of Special Education Programs issued guidance regarding the education of deaf or hard of hearing students specifying that special factors should be taken into consideration when developing a child's IEP, and that "meeting the unique communication needs of a student who is deaf is a fundamental part of providing [a free appropriate public education "FAPE"] to the child."¹¹ Additionally, the 1992 guidance states that the IEP Team may need to consider additional factors, such as *curriculum content and method of curriculum delivery* in determining how to meet "the particular needs of an individual child."¹²

Parents have been recognized as vital members of the IFSP and IEP Team.¹³ The IDEA requires a multidisciplinary assessment to determine the "unique strengths and needs of that infant or toddler," as well as a "family-directed assessment" to determine the "resources, priorities, and concerns of the family" and to identify the "supports and services necessary to enhance the family's capacity to meet the developmental needs of that infant or toddler."¹⁴

Part B of the IDEA states that the agency responsible for providing FAPE to the child "must obtain informed consent from the parent of the child before the initial provision of special education...to the child."¹⁵ The IDEA defines consent as the parent being "*fully informed* of all information relevant to the activity for which consent is sought."¹⁶ IDEA regulations and Department guidance also stress that when developing the child's IEP, the IEP team must also consider such factors as the concerns of the parent for enhancing the education of their child, and the academic developmental and functional needs of the child.¹⁷

Accordingly, it is imperative that parents receive all of the necessary information about the range of technology and language development options available to an infant or toddler with hearing loss.

II. Facts Presented

ACI Alliance has learned from firsthand accounts that USDB parents may not be receiving all of the relevant information that is required for them to be "fully informed." Additionally, USDB administrators have created an environment in which staff members are hesitant to provide information on LSL-only communication programs to parents in fear of retaliation. Parents are therefore only receiving limited relevant information regarding the language and modalities available for their infant or toddler with hearing loss.

¹¹ Department of Education, Office of Civil Rights, Notice of Policy Guidance: Deaf Students Education Services (Oct. 26, 1992), available at <https://www2.ed.gov/about/offices/list/ocr/docs/hq9806.html>.

¹² *Id.* (emphasis added).

¹³ *Id.* § 300.321(a)(1); *see also Id.* § 300.322.

¹⁴ *Id.* §§ 303.21(a)(ii)(A)-(B); *see also Id.* § 303.344(b).

¹⁵ *Id.* § 300.300(b)(1).

¹⁶ *Id.* § 300.9(a) (emphasis added); *see also Id.* § 303.7.

¹⁷ 34 C.F.R. § 300.324(a)(1)(i)-(iv).

USDB provides educational services to students who are deaf or hard of hearing from birth to age 21.¹⁸ The school offers programs in Early Intervention Listening and Spoken Language (LSL) and American Sign Language (ASL)/English Bilingual education (hybrid program).¹⁹ In the relatively new “hybrid” program, students spend one week in an LSL-only classroom and one week in an ASL-only classroom, switching between classrooms throughout the school year. While the school advertises the different educational programs on their website, we understand that USDB administrators have increasingly begun to focus funding and resources specifically on the ASL and hybrid programs, while deemphasizing and reducing available resources for the LSL-only program.

ACI Alliance is not aware of any empirical evidence which shows that this hybrid approach is an appropriate method for language development in children who are deaf or hard of hearing. In fact, this approach appears to contradict recommendations from the American Speech-Language-Hearing Association, Joint Committee on Infant Hearing, which found that “there are sensitive periods for the development of auditory skills and spoken language” and that the first five years of a child’s life are critical for language learning in these areas.²⁰ In their 2017 Supplement report, the Committee recommended that families and children who are deaf or hard of hearing should receive the highest level of provider skills at the very beginning of the child’s life in order to optimize this short and sensitive time period.²¹ Switching children between the two classrooms could disrupt the child’s interactions with high level providers and delay language development during this sensitive time period.

Some parents have expressed their concern that USDB is heavily promoting the bimodal language “hybrid” approach over other approaches available at USDB for children with hearing loss. The school no longer offers spoken language mentors for parents and children that participate in the school’s Deaf Mentor program. The school has also discontinued the spoken language-only toddler group, which had been operating for at least 9 years. ACI Alliance has also been made aware of a USDB policy where on certain days, students are only allowed to speak ASL in the lunchroom. Students who are “caught” using spoken language are segregated to a separate lunch table as punishment.

It is our understanding that USDB administrators and staff are not providing the required information for parents to make informed choices for their children. Specifically, we have been informed that USDB administrators and Parent Infant Program (PIP) advisors are *not* informing parents that they have the choice to enroll their child in a LSL-only program, and are guiding—or perhaps, pressuring—parents to place their child in a bimodal, hybrid communication program instead.

¹⁸ Utah School for the Deaf and the Blind, *Utah School for the Deaf*, available at <https://www.usdb.org/programs/deaf-and-hard-of-hearing> (last visited July 30, 2019).

¹⁹ *Id.*

²⁰ American Speech-Language-Hearing Association, *Supplement to the JCIH 2007 position statement: principles and guidelines for early intervention following confirmation that a child is deaf or hard of hearing* [Position Statement] (2013). Available at www.asha.org/policy.<https://www.asha.org/policy/PS2013-00339>.

²¹ *Id.*

We have also been made aware of instances in which LSL teachers at USDB are reluctant to speak out about the school's current policies, and implementation of such policies, or feel pressured not to share or promote necessary information with parents about spoken language techniques and opportunities. Parents have also expressed their concerns that USDB staff members are reluctant to report allegedly noncompliant or unethical practices by USDB administrators for fear of retaliation for speaking out.

Many times, when parents make decisions that can have life-long consequences for a child who is deaf or hard of hearing, they feel overwhelmed and rely on professionals and specialists to help make the decision that is right for their child and family. However, parents and former USDB employees have informed us that not only are USDB parents misinformed of the educational and language opportunities available for their children, but USDB administrators and PIP advisors are telling parents that ASL is essential for their child's language development and that spoken language *must* be combined with ASL for their child to be successful. In one example, one parent reported being told by USDB staff that her daughter "only had a narrow window to learn language, so she should learn ASL quickly."²² The administrator then told a story where a young man was "forced" to learn LSL which he did not learn as easily as sign language and that this "made him become suicidal and ask that his Mom not attend his graduation."²³

III. Policy Interpretation

At such a vulnerable time in their child's life, a lack of accurate, objective information can lead parents to provide uninformed input and consent regarding early intervention services without learning about cochlear implant technology and language development options available to them. ACI Alliance therefore seeks a policy interpretation by the Department of the following applicable regulatory IDEA requirements in the context of the specific facts presented.

1. Consistent with the provisions applicable to IEPs and IFSPs requiring a focus on the unique needs of the individual and the "special factors" applicable to deaf or hard of hearing students:
 - Is it appropriate to promote one language and modality program over other programs that are available at USDB?
 - Is it appropriate to require children to participate in ASL-only activities if the parents choose to place their child in the LSL-only program?
 - Is it appropriate to claim the USDB curriculum is based on research principles without providing empirical evidence?
 - Is it appropriate to segregate children from their peers in the social lunch room setting if they wish to speak or if they do not know ASL?

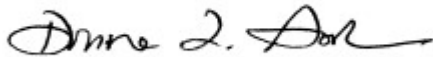
²² Letter from Sabrina Parrish, mother of a toddler in the PIP program, submitted to the Utah State Board of Education requesting an investigation of USDB. The request was filed in January, 2019; however the State Board of Education has not yet acted on the request.

²³ *Id.*

2. Consistent with the provisions applicable to parents, particularly provisions requiring that parents be “fully informed,” how are parents expected to provide informed input regarding the proper language and modality program for their child if:
 - The school does not provide the same mentorship opportunities and parent support programs for all modalities?
 - Teachers feel precluded from giving appropriate information to parents regarding the educational opportunities available for the child?

We appreciate your attention on this important matter, and look forward to your interpretation. For questions, please contact our Executive Director, Donna Sorkin, at Dsorkin@ACIAAlliance.org.

Sincerely,



Donna L. Sorkin MA
Executive Director
American Cochlear Implant Alliance

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