

**Your Name**

Your City, ST 12345

(123) 456-7890

My name is [your name], I am here with other families representing FACE for DeafBlind and I am one of your constituents. I would like to discuss this agenda and the needs of my child who is DeafBlind, [name] who is [##] years old. [Give a brief statement about why this is so important to your child]

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# OVERVIEW

This national advocacy agenda developed by family leaders representing eleven (11) family organizations from across the United States[[1]](#footnote-0). Many of those same family leaders are continuing their advocacy efforts through the Family Advocacy Coalition Educating (FACE) for Deaf-Blind. We feel that this agenda expresses a common need for our Deaf-Blind children, regardless of etiology.

# GOALS

1. Ensure accessibility to a free and appropriate public education for children who are Deaf-Blind.
2. Ensure opportunity for adults who are Deaf-Blind to have a purposeful life of their choice.

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# SPECIFICATIONS

1. Require States to include “services to students who are Deaf-Blind in **special education State Plan**s” via addenda to existing plans & inclusion in future State plans. The plan should include:
	1. Definition – We recommend adding this [definition](https://docs.google.com/document/d/1CVyN7lL3jCG9xKcj0uKQUX-_WkCiufU1g4lfEUDSc_0/edit) to the [existing definition in IDEA](https://sites.ed.gov/idea/regs/b/a/300.8/c/2)
		1. Justification - To ensure that our children are properly identified in the child count, which determines allocation of funds to our state Deaf-Blind projects.
	2. [Qualified Personnel](https://www.nationaldb.org/national-initiatives/iqp/) - We suggest that qualified personnel include Teachers of Students who are Deaf-Blind and Interveners
		1. Justification - For our children it’s not Deaf PLUS Blind, it’s Deaf TIMES Blind, as the dual sensory loss has an exponential impact. They have very unique needs and require teachers certified in Deaf-Blindness to help them navigate the educational system. Please read NFADB’s [Position Paper on Qualified Personnel](https://docs.google.com/document/u/0/d/1gUvDu1gfn8_OHQJXyEGaZMCN32bDRzbibvYdnJ4j9gg/edit).
	3. [Interveners](https://www.nfadb.org/resources/document/uTljNHN_T9II2VPclRSi4ZcHdaQZApLgCVtNxCwtZR1HCnc1q2f-EL45SI3QiblOarze7It4adSDQ3-wpKhIIw2?token=2fb4e7ab2c5b9ba71be008e37c9d7e2b) - We propose that Interveners be written explicitly in the list of permitted [related services](https://sites.ed.gov/idea/regs/b/a/300.34) for all Deaf-Blind
		1. Justification - Interveners are trained to provide access to environmental information necessary to ensure a free appropriate public education to children who are Deaf-Blind. Please read NFADB’s [Position Paper on Interveners](https://www.nfadb.org/resources/Documents/Intervener%20Position%20Paper_a.pdf).
	4. Technical Assistance - We urge the Department to provide funding for technical assistance ( i.e., [NCDB and State Deaf-Blind Projects](https://www.nationaldb.org/for-state-deaf-blind-projects/)) at levels commensurate with the needs of students who are Deaf-Blind and their families.
		1. Justification - Families would be lost without State Deaf-Blind projects. The projects provide a range of services to improve results for us and our children who are Deaf-Blind.
	5. [Transition plans](https://www.nationaldb.org/info-center/educational-services/transition-planning/) - We request that transition plans to adult life align with a **State Plan for Adults**.
		1. Justification - Transition planning is mandated by IDEA and helps youth with Deaf-Blindness get ready for college, vocational training, employment, and community life once they leave school. The plan does not necessarily follow the child into the adult setting, leaving family members scrambling to piece things together.
2. Require States to develop a **State Plan for Adults** who are Deaf-Blind. Ensure the timely implementation of appropriate services and supports for adults who are Deaf-Blind for a successful transition from school to adult life, including but not limited to post-secondary education, the workforce, or other settings. [[2]](#footnote-1) The goal is a purposeful life of their choice. The plan may include:
	1. We highly recommend that the state plan for adults be coordinated with the **Special Education State Plan** (initially)**.**
		1. Justification - Our education team works hard to develop a transition plan to ease our children into adult life. The effort is lost if adult services are not in sync with that transition plan.
	2. We request that the state plan include the [array](https://www2.cmich.edu/colleges/class/Centers/DBCentral/Documents/Comparison_of_Supports_6.22.16.pdf) of [support services](https://rid.org/supporting-individuals-who-are-deafblind/), to include SSPs/CNs, Interveners, and Interpreters necessary to provide information, access, and communication required.
		1. Justification - Individuals who are Deaf-Blind require access to their environment and facilitation of communication with people encountered in their surroundings.
	3. We propose that all states offer a Deaf-Blind Medicaid [Waiver](https://www.hhs.texas.gov/sites/default/files/documents/doing-business-with-hhs/providers/long-term-care/dbmd/what-is-dbmd.pdf) to adults who are Deaf-Blind.
		1. Justification - Individuals who are Deaf-Blind have unique needs and some need additional support to maintain their independence in their community, rather than live in a long-term care facility.

We thank you for your interest in ensuring that all individuals who are Deaf-Blind reach their full potential. We appreciate all that you do to prepare our children and families. Please reach out to us if you have any questions regarding our continued advocacy efforts.

1. National Family Association for Deaf-Blind, Usher Syndrome Coalition, CHARGE Syndrome Foundation, Global Foundation for Peroxisomal Disorders, Ava’s Voice, Deaf-Blind Multihandicapped Association of Texas, Texas Chargers, Inc., Arkansas Empowering Families with DeafBlindness, PA Partnership for the DeafBlind, Family Partners for DeafBlind of Florida & US Virgin Island, and New York Parent Association for the DeafBlind. [↑](#footnote-ref-0)
2. The [Developmental Disabilities Assistance and Bill of Rights Act of 2000](https://acl.gov/sites/default/files/about-acl/2016-12/dd_act_2000.pdf) provides funds to support the development of a 5-year State strategic plan to include a comprehensive review and analysis of the extent to which services, supports, and other assistance are available to individuals with developmental disabilities and their families. The law does not, however, require state coordination of service agencies/providers nor does it require any coordination/collaboration with providers of public-school transition for students with disabilities. [↑](#footnote-ref-1)