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IDEA State and Local Implementation Study 2019- Docket No.: ED-2019-ICCD-0050

Dear Director

The National Down Syndrome Congress (NDSC) is the oldest national organization serving individuals with Down syndrome, their families, and the professionals who work with them. We represent approximately 350,000 individuals living with Down syndrome in the United States and worldwide and are the leading national organization providing resource support and information for anyone touched by or seeking to learn about Down syndrome, from the moment of prenatal diagnosis through adulthood. Through our mission of providing information, advocacy and support concerning all aspects of life for individuals with Down syndrome.

We are submitting this letter in response to the Institute of Education Sciences (IES) notice requesting public comments regarding the Individuals with Disabilities Education Act (IDEA) State and Local Implementation Study 2019. Our comments focus on several key issues, but NDSC also supports the more extensive comments submitted by the Consortium for Citizens with Disabilities.

ALL Stakeholders must be included in the data collection

NDSC takes the position that any activities undertaken by The U.S Department of Education (ED) to provide an up-to-date view of IDEA implementation must be designed in such a manner as to capture the views of all critical stakeholders.

As proposed, this survey and the study that will communicate its findings will provide information drawn *only from administrators of special education, at the state, district and school levels*. While input from these stakeholders is important, it should not and must not be portrayed as representative of *all stakeholders*.

In particular, we wish to highlight the lack of involvement of parents of children with disabilities and those who work closely with parents and families in the states. One of the stated purposes of the implementation study mandated by Congress was to measure "the effectiveness of schools, local educational agencies, States, other recipients of assistance under this chapter, and the Secretary in achieving the purposes of this chapter by improving the participation of parents of children with disabilities in the education of their

children.” (Section 1464(b)(2)(D)(viii)). Significant among the “other recipients of assistance” are the Federally-funded Parent Information Centers. Currently funded at \$27.4 million annually, these Centers have been in continuous operation for decades, building strong relationships with families and other agencies that provide services to children and youth with disabilities. Parent Centers compile and report copious data on their work with families. Given their years of experience, Parent Centers are uniquely qualified to provide information on how states, districts and schools are implementing IDEA. Parent Centers could also serve as a means to obtain valuable input from parents.

Given that the IDEA confers rights on parents and emphasizes their role as a meaningful participant on the child's IEP team, it is a major oversight that ED has not planned to also survey parents with a separate survey tool about the implementation of IDEA. Issues with implementation will not be fully understood or results valid unless families are also included in a national study.

Information that should inform the study

Any study on IDEA implementation should encompass the vast body of information available to IES through these and other sources. For example:

- Annual Performance Reports (APR) submitted by every state.
- State Performance Plan/Annual Performance Report (SPP/APR) Analysis
- Annual Reports to Congress on the Implementation of the IDEA
- Annual State Determinations and Annual LEA Determinations
- Differentiated Monitoring and Support reports
- Civil Rights Data Collection administered by ED’s Office for Civil Rights
- National Center on Educational Outcomes (NCEO) annual reports on participation and performance of students with disabilities on state assessments
- Center for Appropriate Dispute Resolution in Special Education (CADRE) annual reports on dispute resolution by states
- Reports on critical IDEA implementation issues produced by the Government Accountability Office (GAO)
- Reports produced by the National Council on Disability (NCD) on IDEA, including a 2018 series
- National Assessment of Educational Progress (NAEP)
- Reports by the Education Commission of the States, including a 2019 report providing a 50-state comparison of K-12 education funding
- Reports by the Congressional Research Service

Transparency

NDSC urges ED to make any surveys conducted by IES regarding IDEA implementation available to the public. This would include all identifying information (State, district, school names) unless doing so could reveal personally identifiable information.

LRE and FAPE as part of the data collection

It is critically important that the issue of LRE implementation be explored in any comprehensive study on state and local IDEA implementation, particularly for students in

the intellectual disability (ID) category and, if possible, students who take alternate assessments.

A recent article in the University of Minnesota Impact magazine by Harold Kleinert, Director Emeritus of the Human Development Institute, University of Kentucky, provides troubling data on the failure of states and districts to implement the Least Restrictive Environment provisions of IDEA for students with significant cognitive disabilities. As the data shows only 17% of students in the intellectual disability category are educated 80% or more of the day in general education classrooms. The data is far worse for students who take alternate assessments—only 3% educated in general education classrooms. This is consistent with the information we hear from families where the diagnosis of Down syndrome, an IQ score and/or the fact that the student takes the alternate assessment are inappropriately used to determine placement. We recognize that data is not generally collected regarding LRE based on participation in the state alternate assessment, but there is already data on LRE by disability category that can be explored. It is impossible to believe that LRE decisions are being made properly when the result is such widespread segregation of certain students. <https://ici.umn.edu/products/impact/312/Least-Restrictive-Environment-Data/#Least-Restrictive-Environment-Data>

It is also important to study whether these students are receiving a free appropriate public education (FAPE). The Every Student Succeeds Act (ESSA) makes it clear that students who take alternate assessments are expected to be instructed and assessed on the content standards for the grade in which they are enrolled and are not to be precluded from attempting to complete the requirements for a regular high school diploma. These requirements should inform what is considered to be an appropriate education under IDEA. Any study on state and local implementation of IDEA should be looking at whether the curriculum being used and teacher preparation/staff development are designed to achieve this result for these students (e.g. through Universal Design for Learning, PBIS and other frameworks). What we hear from families is that there is still far too much focus on “functional life skills curricula” at the expense of an academic education through which functional skills can also be gained. The term “alternate curriculum” is too often used to justify non-inclusive placements even though under IDEA and ESSA the only curriculum mentioned is the general education curriculum. It is also important to determine whether students are receiving the tools and services they need for communicative competence; an essential element of FAPE.

Universal Design for Learning (UDL)

A question should be added to the data collection asking schools and districts whether they are implementing UDL. While IDEA does not require the use of UDL in schools, UDL is essential to providing a free, appropriate public education (FAPE) in the least restrictive environment for students, allowing them to access the general education curriculum.

Additionally, many states have indicated in their ESSA plans that they are implementing UDL as a means to facilitate inclusion and ensure students have access to grade-level standards. This survey presents an opportunity to determine whether UDL is being implemented as planned in schools across the country.

The UDL language in ESSA plans is reported in this document:

https://docs.google.com/document/d/1NSs9NV1sNuNwO2aEEJ3HXf2Y17HGW_yvjY370y7Gn4A/edit

Alternate Assessments

Three questions on alternate assessments should be added to the surveys. One question should collect data on the criteria used by IEP teams to determine eligibility for alternate assessments on alternate academic achievement standards (AA-AAS).

The second question should ask for information on state and local policies, consistent with ESSA, which are designed to ensure that students who take these alternate assessments are not precluded from attempting to complete a regular high school diploma. If this ESSA requirement is not implemented it impacts the provision of FAPE under IDEA.

The third question should ask whether states are using a standardized AA-AAS. If so, they should list whether they are using the assessment designed by the National Center and State Collaborative or Dynamic Learning Maps, or list any other standardized assessments. IDEA requires that IEP goals for all children with disabilities must be aligned with grade-level content standards. Alternate academic achievement standards must also be aligned with grade-level content standards. The Department of Education funded testing consortia to develop assessments to meet the common core standards, which have been adopted, at least in part, by a majority of states. Two of these consortia developed AA-AAS - the National Center and State Collaborative and Dynamic Learning Maps - to standardize assessments for students with the most significant cognitive disabilities and move away from the more subjective measures such as portfolios and teacher rating scales. Standardized assessments allow for greater comparability of proficiency for this population across schools, districts, and states.

NDSC appreciates this opportunity to submit comments regarding the Individuals with Disabilities Education Act State and Local Implementation Study 2019. If you have any questions, please contact me at ricket@ndscenter.org.

Sincerely,

Richelle (Ricki) Sabia



Senior Education Policy Advisor
National Down Syndrome Congress