



Down Syndrome Caucus Hearing
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EDUCATION ISSUES FOR INDIVIDUALS WITH DOWN SYNDROME

As advocates for individuals with Down syndrome it is our responsibility to ensure that they have the opportunity to receive an education that will prepare them for fulfilling and productive lives, as members of their community and citizens of this country. Children with Down syndrome now look forward to a future that was unimaginable before the Individuals with Disabilities Education Act. In spite of this good news, there is still much work to be done to preserve the gains we have made and to make even greater strides toward the future.

IDEA

Funding

One persistent issue under IDEA has been the lack of adequate funding. The excess cost of educating students with disabilities has never been federally funded at higher than 18% until the recent influx of funding in the stimulus package. This is true even though 40% was promised when IDEA was enacted more than 30 years ago. We are very grateful for these supplemental funds. However it is extremely difficult to improve educational opportunities for students with disabilities when local education agencies are permitted by IDEA to lower their expenditures by up to 50% of any funding they receive that exceeds the amount of funding in the previous year. As soon as the federal government provides extra money, half that amount can disappear to be used elsewhere, even when the district and the State are not in compliance with the requirements of IDEA. This is particularly disheartening to parents of children with Down syndrome who spend an enormous amount of time battling the effects of this non-compliance. We need to tie this flexibility to compliance and fully fund IDEA.

Evaluations

Students with Down syndrome often fall through the cracks of many of IDEA's key provisions. For example, evaluations are supposed to be used to determine the category of disability and the evaluation tools are supposed to be valid for the purposes for which they are used. However, children with Down syndrome are being evaluated for the mental retardation (MR) eligibility category of IDEA using assessments that require greater expressive language abilities than they generally have. The children's language limitations keep them from answering questions that are supposed to assess their cognition not their language. Parents generally have good reason to believe that the scores do not reflect their child's true cognitive abilities.

We need research to develop appropriate evaluation tools and stronger language in IDEA to promote their use. It is also important to make the use of the developmental disability category mandatory for the States and districts so that students aren't put in the MR category when they are too young to make that determination.

Educational Setting-Least Restrictive Environment

Using current evaluations, nearly all children with Down syndrome end up in the MR category. This eligibility determination is not supposed to determine their placement. Least Restrictive Environment (LRE) decisions under IDEA are required to be individualized. In addition, IEP teams are required by IDEA to consider the general education classroom first and then consider more restrictive placements only if the child can't be satisfactorily educated there even with supplementary aides and services.

Unfortunately, the 2007 IDEA data shows that nationwide only 15% of students in the MR category are being educated in the general education classroom more than 80% of the day, with 14 of the states coming in at less than 10%. For example, Washington State is at 4.76%, D.C. is at 6.07%, Texas is at 6.95%, but Rhode Island is at 23.28%. Nationally almost 50% of the students in this category spend less than 40% of their time in the general education classroom.¹ Sometimes it is appropriate to educate a particular child in a separate class, but that decision must be made using the appropriate process and not because of the child's category of disability or because the teachers do not have the training and supports to educate the child in the general education classroom.

In the next reauthorization of IDEA it is imperative to clarify that disability category must not determine placement decisions and to require documentation that the proper LRE process is being followed by IEP teams. Also, States should be required by IDEA to report the progress they are making on the provision of a free, appropriate, education in the LRE across the disability categories, instead of just looking at the aggregate results. In addition, more parent involvement should be incorporated in the monitoring process to address LRE and other issues. Some will have you believe that compliance is not about outcomes, but our children will not have positive outcomes until there is compliance.

¹ www.ideadata.com, see numbers for the 50 states plus D.C. For students with disabilities in the aggregate these numbers are reversed—56% in the general education class more than 80% of the day, 15% less than 40% of the day.

Preschool Inclusion

The LRE provisions in IDEA also apply to preschool age children, however, we need to have greater clarity in the law about the responsibility of districts to provide inclusive opportunities for preschool age children. Parents often pay for a private inclusive preschool without reimbursement, even though the district is responsible for providing an inclusive option when appropriate and they offer no appropriate public inclusive options. The preamble to the IDEA 2004 regulations recognizes this responsibility but it was not clarified in the body of the regulations.

Transitional Postsecondary Education Programs

Many of our self advocates can tell you in their own words that they want to go to college like their friends and siblings. It is often the appropriate place for them to be educated with same age typical peers, especially with the support of transitional programs that have been developed for these students.² Studies have shown that a postsecondary school experience provides many of the same benefits for students with intellectual disabilities as it does for typically developing young adults; preparation to live independently and be successfully employed. The Higher Education Opportunity Act recognized these benefits when it established model demonstration projects for these students.

Statutory changes are necessary to explicitly clarify that districts can use IDEA and vocational rehabilitation funds for these postsecondary programs. The preamble of the IDEA 2004 regulations indicates that this is an appropriate use of IDEA funding. We need a joint memo from the Office of Special Education Programs and the Rehabilitation Services Administration until the statutes are amended.

Procedural Safeguards

One of the pillars of IDEA as a civil rights law is the section on procedural safeguards. As long as children with Down syndrome continue to have their placement and instruction based on their disability instead of their abilities, are subject to the discipline provisions that no longer consider whether they understood the consequences of their actions, are in schools where seclusion, restraint and aversives are used instead of positive behavioral supports; parents will be forced to protect their child's rights through due process. Due process is always a last resort. Anyone who honestly thinks that parents are litigious has not seen the data on how small the percentage of cases actually is and does not understand the emotional and financial toll that due process takes on a family. On September 9, 2003, the General Accounting Office (GAO) reported that overall the number of disputes are few with about 5 due process hearings per 10,000 students with disabilities and 7 mediations per 10,000 students with disabilities.³

The due process provisions in IDEA are highly complex and almost impossible to navigate without an advocate or attorney. Recent Supreme Court cases have stacked the

² See www.thinkcollege.net for information on these programs.

³ <http://www.gao.gov/new.items/d03897.pdf>

deck even higher against parents, especially those who can't afford attorney and expert fees. We are very grateful that Congressman Sessions, along with Congressman Van Hollen, has co-sponsored the IDEA Fairness Restoration Act. This bill seeks to restore the parent's right to be reimbursed for expert fees if they prevail in their case. The provisions in this bill should be added to IDEA along with provisions putting the burden of proof back on the school district in due process cases since most of the witnesses are their employees.

NCLB

NCLB is based on the premise that all children can be proficient on their State content standard. A very limited percentage of students with disabilities may need to be assessed using different achievement standards, but they are all expected to receive instruction aligned to the State content standard for the grade in which they are enrolled. This premise makes NCLB more than an accountability statute; it is the institutional embodiment of the high expectations that students with disabilities need to succeed. There are those who assert that NCLB has had a negative impact on children with disabilities. On the contrary, with its focus on accountability and the requirement to disaggregate data by subgroup, it is one of the best things to have happened in a very long time. The negative impact comes from scape-goating and low expectations perpetrated by those who do not want to be held accountable for children with disabilities or engage in the hard work that it will take to implement this law properly. The accountability provisions for students with disabilities, including those who are assessed on alternate academic achievement standards, must be kept strong so that these students do not get swept back under the rug.

In 2003, regulations for NCLB permitted the development of these assessments on alternate academic achievement standards for students with the most significant cognitive disabilities. In an effort to keep them from being overused, the Department put a cap on the number of proficient or advanced scores from these assessments that could be used towards AYP. This cap is equal to 1% of all students being assessed. Since the assessment is only used for students with disabilities this translates into 10% of these students. In the original proposed regulations this cap was .5%, a figure more consistent with the data on how many students have the most significant cognitive disabilities, but was doubled as a result of State objections to the lower cap. There is no cap on the percentage of student with disabilities who can be given the test.

We were very concerned about the implementation of this regulation because every child with Down syndrome could end up in this assessment, whether or not that is appropriate. Although there is no data collection on the percentage of students with Down syndrome who take this assessment, the anecdotal evidence indicates that it is an extremely high percentage. At first the Department seemed to be making an effort to keep the standards high for the alternate academic achievement standards. Most of the details were fleshed out in non-regulatory guidance or in practice, but not explicitly in the regulations.

Unfortunately, this became an alarming problem when the regulations for the modified academic achievement standard were developed. A great many protections were explicitly put in place in those regulations, many of which were always assumed to be in place for the alternate academic achievement standards. Now, by contrast to the regulations on the modified academic achievement standard, those protections could be interpreted as not applying to the alternate academic achievement unless explicitly mentioned. It is imperative to amend the regulations for the alternate academic achievement standards, especially if they are to be codified in the reauthorization of NCLB, to add these protections. A paper on the necessary amendments can be found on the NDSS website.⁴ The three provisions that concern us the most state that:

- ✚ Access to the curriculum is promoted (but does not say it is “provided” as it says for the modified academic achievement standards);
- ✚ The alternate academic achievement standard is aligned to the grade-level content standard (but does not specify alignment to the grade-level content standard *for the grade in which the child is enrolled* as is specified for the modified academic achievement standard).
- ✚ Students assessed on the alternate academic achievement standard are included in the general education curriculum *to the extent possible*. We believe this language violates IDEA.

In addition to having their access to the general education curriculum threatened, students with Down syndrome who are assessed on alternate academic achievement standards are made more vulnerable in other ways that must be addressed. In many states students who take this assessment are precluded from working towards a regular diploma. If these students are together in a special education classroom, their teacher is permitted to have lower qualifications for the highly qualified teacher requirements. This point will be discussed in greater detail in the next section of the paper. These students generally do not participate in the National Assessment on Educational Progress (NAEP). In addition, there is a proposed NCLB amendment on graduation rate concerning students who have proficient or advanced scores on assessments based on alternate academic achievement standards. All these students would be counted as if they received a regular diploma. In fact, most of them will receive nothing more than a certificate stating that they have attended classes for 12 or more years. The school will have no incentive to try to help them earn a diploma.

Instruction-Universal Design for Learning (UDL)

Although expectations for students with Down syndrome have improved since the enactment of NCLB, the problem persists. As I have mentioned, if they are in a separate secondary school classes for students who take assessments on alternate academic achievement standards, IDEA holds their teachers to lower professional standards than other highly qualified educators. Their teachers are only required to be certified at an elementary school level and are not expected to be qualified to teach the grade level content, even though NCLB requires their assessments to be aligned to the grade level content standard. Although the teachers in general education classes have more content training than special education teachers, they usually do not have the training or

⁴ <http://www.ndss.org/images/stories/NDSSresources/pdfs/nclbregs1language.pdf>

experience to teach students with intellectual disabilities and also have low academic expectations.

It is very difficult to raise expectations and improve instruction when the curriculum is not designed to be accessible for all students. Teachers often do not have the time or the knowledge to make the inflexible curriculum and limited instructional materials work for many of their non-disabled students, so we shouldn't be surprised that they struggle when students with disabilities are also in the classroom. Some educators try to retrofit the curriculum. Often the result is that the child is pulled out to a resource room or sits to the side of the classroom or in the hall with an aide working on separate assignments. The student gets frustrated and sometimes behavior problems begin. The teacher gets frustrated and believes the child doesn't belong in the class. The parents are frustrated and heartbroken. It doesn't have to be that way.

Using Universal Design for Learning (UDL), curriculum can be designed from the beginning to ensure that barriers caused by disability or limited English proficiency are reduced; extra challenge is provided to students who need it; learning is supported; students gain knowledge, skills, and enthusiasm for learning; and their learning is validly assessed. UDL is a scientifically valid framework and set of principles to provide ALL students equal opportunities to learn. It allows educators to choose from a menu of tools and strategies embedded in the curriculum. The three UDL principles are based on neuroscience. In order to simultaneously engage the three networks in the brain that are needed for optimal learning, the curriculum must provide multiple means of presenting information, multiple means for students to express what they have learned and multiple means of engagement. Using these three principles, UDL embeds flexibility into the four components of the curriculum: goals, teaching methods, instructional materials and assessments.⁵

UDL is supported by a broad group of education stakeholders. Twenty-eight national disability and general education organizations (including NEA, AFT, and the National School Boards Association) have come together as the National UDL Task Force to promote UDL in legislation and other education policy. This Task Force is led by NDSS. Some of the other members from the disability community are NDSC, Easter Seals, the Arc/UCP and organizations representing special educators, State Directors of Special Education and students with learning disabilities and autism. For a complete list of members and more information on the Task Force see www.udl4allstudents.org.

The Task Force has recently been successful at incorporating UDL language into the Higher Education Act. We have also recommended language for the reauthorization of the NCLB and hope to add UDL to IDEA. Currently IDEA has references to universally designed assessments and universal design as it relates to product use, but not the comprehensive accessibility of UDL.

Students with Down syndrome have a great deal to gain from UDL. If evaluations were universally designed they would use tools that were accurate for students with language

⁵ www.cast.org

delays. If the curricula goals were universally designed, there would be a variety of means by which to reach the goals depending on the strengths of the students. If instructional materials were universally designed, students would have access to a variety of materials and media with different levels of difficulty and supports to help them gain as much knowledge as possible while keeping the rigor high. The use of technology would also be increased, which engages the students and helps them become 21st century learners. If teacher methods were universally designed, educators would have the skills and the tools to provide access to the grade-level curriculum to diverse learners in a special education or general education classroom. If assessments were universally designed, students with Down syndrome could show educators and administrators just how much they know. The assessment would be a test of their knowledge, not their disability.

Some districts and States have started initiatives on UDL but they are moving too slow. Our students can't wait. We need to add language to NCLB and IDEA that would support additional research on UDL and implement these practices in the State and district strategic plans. There should also be grants for teacher preparation and staff development regarding UDL. In addition, we need amendments to the National Instructional Materials Accessibility Standard (NIMAS) provisions in IDEA. Many wonderful products are being created using the NIMAS files. However, the files and the products are often not available to students with Down syndrome and other disabilities because the NIMAS provisions are too narrowly focused on other specific populations.

Data on UDL implementation should be considered as part of IDEA monitoring. It would help determine if students are getting a free appropriate public education (FAPE). How is FAPE possible if the curriculum is not accessible? For too long FAPE has been equated with a very minimal level of educational benefit. In part this is because no one knew how to ensure that students with disabilities received any greater benefit. Thanks to UDL that is no longer true.

Conclusion

ALL students in this nation, including children with Down syndrome, deserve a high quality education. If the issues raised today can be addressed, children with Down syndrome will have the opportunity to live up to their potential instead of being hampered by low expectations.

