

Pre-conference Learning: Education

April 17, 2023



national down syndrome society®

**Down Syndrome
Advocacy
Conference**

Advocacy Partner: National Down Syndrome Congress



Session Agenda

- Primer on Disability and Education Policy
- Panel – Current Issues in Education
- Q&A
- An Illustration of Advocacy

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Primer on Disability and Education Policy

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HISTORY OF IDEA

And How Families and Self-Advocates Saved the Law

*Down Syndrome Advocacy
Conference*

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National Down Syndrome Congress

April 17, 2023

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Before the IDEA

- Only one in five children with disabilities was educated
- .
- More than 1.75 million children with significant disabilities were excluded from the education system
- .
- Another 3.5 million children with disabilities did not receive appropriate services
- .
- Close to 100,000 children were in institutions

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The Stage is Set for IDEA

- Federal, state and local legislation, judicial cases, and family advocacy led to PL 94-142.
- Families unite and advocate:
 - Parent Groups met in 1950 in MN to form what is now called The Arc
 - National Down Syndrome Congress founded in 1973
 - Parent groups advocated for state laws and collaborated with disability law groups to file law suits
- .
- 2 successful US district Court cases in 1971
 - *PARC v. Commonwealth of PA* – The court ruled that the state could not deny an individuals right to equal education based on an intellectual or developmental disability. Case helped establish “free appropriate public education” (FAPE), “zero reject” and “least restrictive environment” (LRE). *Cited 1954 Brown v Board of Education* Supreme Court case.
 - *Mills v Board of Education of DC* expanded right to FAPE to other disabilities.
- 27 federal lawsuits followed these cases prior to 1975.

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First Version of IDEA Passes in 1975

- First version of federal special education law – P.L. 94 142, The Education for All Handicapped Children Act (EHA) – passed in 1975 on bipartisan vote and signed into law by Pres. Ford. (Later renamed IDEA)
- .
- A civil rights law based on the 14th Amendment to constitution.
 - Requires FAPE for all in LRE, (Individualized Education Programs (IEPs), and ensures due process and procedural safeguards
 - Part B permanently authorized and includes state grants – assists states in fulfilling their constitutional responsibility to education students with disabilities (SWD)

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Challenges to New Law

- Newly elected President Reagan's budget proposal in 1981 would have consolidated special education programs authorized under P. L. 94-142 and forty-four other education programs into state block grants and drastically reduced total special education funding.
- After protests from advocates and Members of Congress the proposals were withdrawn.

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More Challenges

- In 1982 the Reagan Administration issued proposed regulations for PL 94-142 that would have drastically diminished important provisions and rights in the regulations.
- Letters to ED from 350 Members of Congress and over 100,000 letters from advocates to ED and Congress opposed proposed regulations.
- Proposed regulations beaten back.

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Daughter Laura Jean Elizabeth Lee

1982 – 2016



- No info on Down syndrome but support from other parents
- First two years in hospital: was first refused operation then 2 open heart surgeries (and more later)
- Urged to “put her away” and told everything she would not do



TIP: Don't accept negative assumptions – presume competence

Progress During 1980s

- After tumult, in 1983, Reagan brought in Madeleine Will, a parent, as OSERS Assistant Secretary (who served until 1989).
- Will's priorities included:
 - Inclusion initiative and teacher training
 - Early intervention and preschool services
 - Transition Services
 - Supported employment
- All of these priorities were included in reauthorizations. Continued improvements to the law in several reauthorizations on bipartisan basis. Law's name changed to IDEA in 1990.
- Sen. Weicker, a parent, played key role in funding.

TIP: Identify and nurture champions!

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1984 - President Reagan signed a resolution proclaiming Oct 1984 as National Down Syndrome Month.



L to R – Senator Lugar (R-IN), Madeleine Will, OSERS Assistant Secretary, George Will, parent, Diane Crutcher, NDSC Executive Director, and Tom O'Neil, NDSC President

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National Scene Changes in Early 1990s

- 1994 election - Republican Revolution and Rs control both House & Senate: Gingrich new Speaker of the House with Tea Party and Contract with America.
- Big Congressional turnover and staff cuts – few familiar with IDEA.
- Unfunded Mandate Reform Act of 1995 passed – some referred to IDEA as an unfunded mandate – it is not.
- FY 1996 ED appropriations included drastic cuts. Federal government shut down twice and 13 stopgap spending measures, called continuing resolutions, were passed to keep programs operating.

TIP: Maintain positive relationships with Members in both parties and frame your message to appeal to all.



A Perfect Storm for Reauthorization

- 1993 US Department of ED told Virginia it could not cease educational services to students with disabilities who misbehaved in school, even if misconduct not caused by the child's disability - \$50 mil to be withheld. 1994 court gave temporary reprieve to VA.
- Part B permanently authorized - discretionary parts to expire in 1994.
- IDEA amended through other laws. Statements in hearings, and House 1994 IDEA bill showed that Congressional Democrats and Republicans wanted negative IDEA amendments.
- Gang of 6: the American Association of School Administrators (AASA), the American Federation of Teachers (AFT), the National Association of Elementary School Principals (NAESP), the National Association of Secondary School Principals (NASSP), the National Education Association (NEA), and National School Boards Association. Wanted changes to funding, "school safety", expulsion, attorneys fees, paperwork reduction (IEPs) and increased "flexibility".

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Coordinated Negative Media Campaign Targets Children with Disabilities



Armed kids in special ed aided by law

Expulsion prohibited if disability at fault

By Mary George
Denver Post Staff Writer

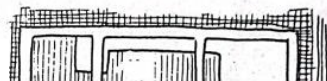
BOULDER — When four Boulder High School students passed a gun around at school last year, administrators pursued the harshest possible penalty: expulsion.

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LETTERS TO THE EDITOR

Troublemakers in Public Schools

The Aug. 10 editorial section offered a number of views concerning disruptive students in public schools.



A Sacred Cow Comes

By Carol Innerst

Congress is about to review one of the most sacred of the sacred cows — special education. The battle on Capitol Hill could be heated. This is the year Congress must reauthorize the Individuals with Disabilities Education Act (IDEA) — the federal government's primary governing special education and one of Congress' largest "unfunded mandates." Whether Congress has the backbone to bring real reform to this law remains doubtful.

IDEA requires school districts to place special education students in the "least restrictive environment" suitable for that student. The regular classroom, in the school the child would attend if not disabled, is considered before a more restrictive placement. Does this matter if it's

SATURDAY, MAY 3, 1997

ST. LOUIS POST-DISPATCH

Bond Targets Disruptive Behavior In Class

■ The Missouri senator found support among educators here for his proposal to tighten rules for disciplining behavior-disorder students.

By Harry Levins

need a parent's permission to suspend a disabled student — permission that often is denied.

Friday's round-table discussion (actually, the table was semicircular) took place at the headquarters of the Ferguson-Florissant School District. There, Bond sat down with 10 superintendents, school board members and police chiefs. Some of them had

can't know the terror of the other children."

Most such horror stories stem from students in a category of disability known as behavior-disorder children. The federal law limits what schools can do when such children act up. In general, Bond's measure would let schools discipline such students in the same way they discipline any

Still, Bond said, "Good education demands discipline and standards of conduct."

That sentiment was uttered more bluntly by Ferguson-Florissant Superintendent Stan Scheer. He told Bond, "We can't teach in chaos."

Scheer's district has had sad experience with chaos. Just a few hundred yards from his headquarters building,

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Bad Bill Racing Through the House

- Disability advocates unable to access offices. Traditional inside the beltway approach not working. Disability groups focused on narrow disability-specific issues. Worked hard but not getting anywhere.
- July 27, 1995, the House education committee issued a staff discussion draft of its bill to reauthorize IDEA. “All Hell broke out.”
- August 1995 NDSC became involved in reauthorization with reports, action alerts, mobilized advocates and meetings with other groups and on the Hill.
- February 1996 bipartisan Senate bill approved by Committee on unanimous vote.
- Senators Ashcroft (R-MO) and Gorton (R-WA) announced will try and amend on the Senate floor.
- April 18, 1996, H.R. 3268, The IDEA Improvement Act of 1996, introduced by Cong. “Duke” Cunningham (R-CA). No Democratic sponsors. On a fast track for committee vote on May 9.

TIPS: Don’t wait for a crisis to get in the door. Inside the beltway advocacy not enough – need grassroots involvement.

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House Consensus Group Emerges

- House Subcommittee voted out a very bad partisan bill on April 24, 1996. Met and joined forces with Madeleine Will and Patty McGill Smith, NPND ED, that day, “Those three women”, as we were referred to, met with general ed group leaders that day and found that we all hated the bill for different reasons. Agreed to work together to try and stop and re-write the bill.
- Action alert from general ed and disability groups and to parents through NPND Friday Fax. Letter to Committee Chair Goodling signed by 26 general and special ed, disability and parent groups.
- “Those three women” met with Chairman Goodling (R-PA) on May 1 and Gang of 6 leaders also met with same request that day.
- On May 2, Mr. Goodling agreed to a consensus group to try and come to agreement on a tight timeline.

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Parents Led House Consensus Process

- House stopped action on bill and allowed intense negotiations. Met 10 to 14 hours per day for 9 days with “Those 3 women” representing parents and moderating. CCD Co-Chairs and other national group leaders at the table.
- On May 14, 1996 the Consensus Group completed its bill. 39 participating groups had reached consensus on over 100 amendments to H.R. 3268, except one, cessation of services for certain students with disabilities. (NSBA and AFT supported cessation.) Over 80 agreed to support consensus.
- House passed bill that did not include many consensus recommendations.
- Disability “Outriders” attacked bill and consensus process.

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Back to the Senate

- Sen. Dole (R-KS) tried on his last day in Congress to get the Senate to pass the bill. Senators Ashcroft and Gorton refused to lift holds. Sen. Lott replaced Sen. Dole as Majority Leader.
- July 1996 Senators Frist (R-TN) and Harkin (D-IA) met with a small group of us and asked consensus group to reconvene. Met, but after threats and demands, disability/parent leaders walked out.
- Asked Dave Hoppe, Lott's Chief of Staff, to help resolve Ashcroft's discipline issue and he did but time ran out to pass a bill during that Congress.

The Hoppe Consensus Process

- Dave Hoppe reached agreement with R and D leaders in the Senate and House to halt the usual Congressional process and have a bipartisan work group
 - Key R and D House and Senate staff and representatives from the Administration would “pre-negotiate” and draft a compromise bill
 - Meetings once a week open to all disability and general and special education advocates. Bipartisan working group decisions would be reviewed with feedback from the field.
 - Hoppe as a neutral facilitator. Work group discussions confidential. No reporters. Deal was everyone in workgroup had to agree to final bill.
- 10 meetings held. Families and self-advocates came from across the country at their own expense from as far away as Hawaii.
- Consensus reached! May 7, House and Senate committees approved consensus bill. May 13 bill passed the House.

TIP: Tell your personal stories tied to the policy objective.

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Last Minute Hitches in Senate

- VA Governor Allen statement on day the bill was before the Senate: “Yesterday Congress languidly bowed to the Clinton Administration in acting to use IDEA to block state and local efforts to ensure discipline and safety in their classrooms and schools. Both the White House and Congress piously claim...” CNN debate with Gov. Allen.
- Two amendments would have gutted civil rights protections and made it almost impossible for parents to be awarded attorneys fees. Amendments lost/were tabled. Consensus bill passed 98 to 1 on May 14, 1997.

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IDEA 1997

- Access to, Participation in, and Progress in the General Curriculum
- Inclusion in State and District Assessments and Alternate Assessments
- Increased inclusion and greater parent role
- Functional Behavioral assessments/plans/positive strategies, interventions, etc.
- Manifestation determinations and NO cessation of services, voluntary mediations
- Increases professional development

TIP: Sometimes advocates stop bad things from happening and sometimes we make improvements possible. IDEA 97 did both.

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IDEA 97 Enrollment Ceremony



Photo by Karmali Lumbard/The Washington Post
Senate Majority Leader Trent Lott and more than a dozen disabled children watch Sen. Strom Thurmond and House Speaker Newt Gingrich sign off on the Individuals With Disabilities Education Act yesterday.



TIP: Always say "thank you" and celebrate!

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IDEA Bill Signing Ceremony at the White House



Clinton finally signs IDEA bill into law

Measure also provides for discipline

By Susan Ferrechio
THE WASHINGTON TIMES

President Clinton yesterday signed into law a measure overhauling the decades-old bill that guarantees an adequate public education for the nation's disabled children.

The Individuals With Disabilities Education Act (IDEA) will require schools to devise more mainstream curriculums and testing for students who are disabled.

"To the 5.8 million children whose futures are in the balance, we are saying: 'We believe in you. We believe in your potential, and we are going to do everything we can to help you develop it,'" Mr. Clinton said to an audience of Capitol Hill lawmakers, disabled students and their parents at a White House ceremony.

"IDEA will ensure disabled students learn with the same curricula and the same assessment as other children," he said.

The law, which revamps the 1975 act, also gives school officials unprecedented authority to remove disabled students who bring drugs or weapons to school.

Yesterday's signing marked the end of more than a year of negotiations between Republican and Democratic legislators, the Clinton administration, parents and advocacy groups over how to craft the new legislation. The measure failed to win support in Congress last year because lawmakers could

not agree how to mete out punishment to disruptive disabled students.

Congress last month approved the measure with overwhelming support after reaching a compromise on that provision.

Under the new law, school officials can immediately remove disabled students who bring drugs or weapons to school, or who are dangerous to themselves or others, for as long as 45 days pending a hearing.

Republican and Democratic leaders noted the bill signified a rare, successful collaboration between the two parties.

The law also aims to partially relieve local school systems of the financial burden of educating disabled students by limiting costly litigation fees that drain their budgets and by making it harder for states to reduce funding levels for special education.

Disabled students will be held to higher standards under the new law, which requires local school systems to develop learning plans that are more closely aligned to the curriculum of non-disabled students.

"The new IDEA helps make sure parents don't have to resort to superhuman deeds to get what they want for their children," said Judith Heumann, U.S. assistant secretary for special education and rehabilitative services, who contracted polio as a child and is paralyzed from the waist down.



Photo by Kevin T. Gilbert/The Washington Times
President Clinton holds the hand of Will McCarthy of Chattanooga, Tenn., after he signed the Individuals With Disabilities Education Act.



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Attempts to Undermine IDEA 97 Began Immediately

- Congress and Secretary under attack to reopen issues resolved in IDEA 97. Groups demanded weakening changes in the law and regulations.
- Either misunderstanding or misrepresenting the law.
- Regulations final after 2 year battle and delay.
- Testified before House Education & Workforce Committee:

TIP: Remember passing the law is just the first step, then appropriations, regulations, guidance and implementation.

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Other Key Laws Impacting the Education of Students with Disabilities

- No Child Left Behind Act of 2001
- Higher Education Opportunity Act of 2008
- Stephen H. Beck, Jr., Achieving a Better Life Experience Act of 2014 (ABLE Act)
- Workforce Innovation and Opportunity Act (WIOA) (2014)
- Every Student Succeeds Act (2015)

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Remember: Self-advocates are the Best Advocates!



MasonLIFE Capitol Hill Interns with Rep. Gregg Harper (R-MS)

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Panel – Current Issues in Education

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Valerie Williams
Director
Office of Special Education Programs,
US Department of Education



Sarah Mueller
Disability Policy Director
Senate Health, Education, Labor, and
Pensions Committee



Mary Christina Riley
Professional Staff
House Committee on Education &
the Workforce



Cyrus Huncharek
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National Down Syndrome Congress



Selene Almazan, Esq.
Legal Director
Council of Parent Attorneys and Advocates





Q&A

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An Illustration of Advocacy

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Michael Holton and Kelli Lee



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Thank you!
Next session:
Employment