



Keynote: How Families and Self-Advocates Saved IDEA

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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

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
 - NDSC founded in 1973
 - Parent groups advocated for state laws and collaborated with disability law groups to file lawsuits
- Brown v. Board of Education, 1954, & 2 successful US district Court cases in 1971
 - *PARC v. Commonwealth of PA* – The court ruled that the state could not deny an individual's right to equal education based on an intellectual or developmental disability. Case helped establish “free appropriate public education”, “zero reject” and “least restrictive environment”. *Cited 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.

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 by Pres. Ford. (Later renamed IDEA)
- A civil rights law based on the 14th Amendment to constitution.
 - Requires FAPE for all in LRE, IEPs, and ensures due process and procedural safeguards
 - Part B permanently authorized and includes state grants – assists states in fulfilling their constitutional responsibility to educate students with disabilities (SWD)

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- After protests from advocates and Members of Congress the proposals were withdrawn
- President Reagan also promised in his campaign to abolish the US Department of Education

More Challenges

- In 1982 the Reagan Administration issued new proposed regulations for PI 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

Daughter Laura Born in 1982



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



TIP: Don't accept negative assumptions – presume competence



NATIONAL
DOWN SYNDROME
CONGRESS

Continued Progress

- 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!

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



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

Virginia Advocacy 1992-1995

- Organized successful bipartisan school district and state-wide advocacy efforts on funding and equitable staffing for students with ID, reducing speech therapy ratios, and retaining civil rights in Virginia regulations
- As a result, district special education funding saved, state legislation passed, new \$3 million per year state funding for students with ID, increased \$ for speech therapy and protected civil rights and parental involvement in VA regs.

TIP: Don't believe experts who say "It can't be done!"

TIP: Reframe the debate in positive terms.

TIP: Organize and mobilize effective coalitions!

National Scene Changes in Early 1990s

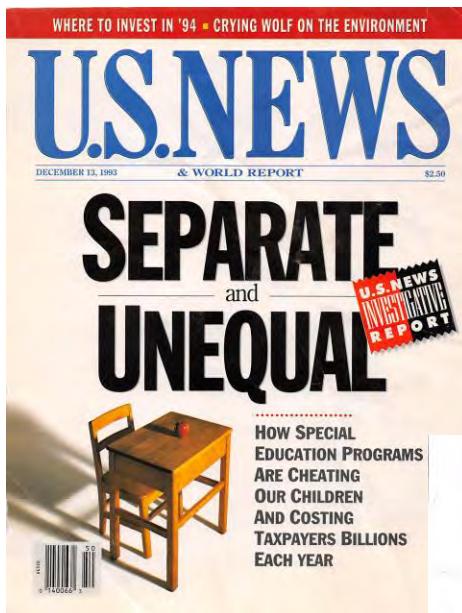
- 1994 election - Republican Revolution and Rs control both House & Senate: Gingrich new Speaker of the House with Tea Party and Contract with America
- Big Congressional turnover and staff cuts – few familiar with IDEA
- Unfunded Mandate Reform Act of 1995 passed – some referred to IDEA as an unfunded mandate
- Proposals to eliminate Department of Education
- FY 1996 ED appropriations included drastic cuts. Federal government shut down twice and thirteen stopgap spending measures, called continuing resolutions or CRs, 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 OSERS 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. Focus on discipline, expulsion, and "cessation of services"
- 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 IDEA amendments, particularly discipline, cost, and "paperwork"
- 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
- Gang of 6 wanted changes to funding, "school safety", expulsion, attorneys fees, paperwork reduction (IEPs) and increased "flexibility"

Coordinated Negative Media Campaign Targets Children with Disabilities



A Sacred Cow Comes

By Carol Innes

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 governing special education and one of Congress' largest "unfunded mandates." Whether 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 where attend if not disabled, is considered before a more restrictive placement. It

natter if it's

WHERE TO INVEST IN '94 • CRYING WOLF ON THE ENVIRONMENT

U.S. NEWS

DECEMBER 13, 1993 & WORLD REPORT \$2.50

SEPARATE and UNEQUAL

U.S. NEWS INVESTIGATING REPORT

HOW SPECIAL EDUCATION PROGRAMS ARE CHEATING OUR CHILDREN AND COSTING TAXPAYERS BILLIONS EACH YEAR

By Richard Whitmire
Gannett News Service

DAYTON — Like other severely disabled children across the USA, the students in Elaine Fouts' class receive a legally guaranteed "appropriate" education that includes teachers, aides, physical and speech therapists. The yearly per-pupil price

Critics say soaring costs for disabled students means of

Special ed: Is the price too high?

HEALTH AND EDUCATION

6D • MONDAY, JUNE 17, 1996 • USA TODAY

Special ed: Is the price too high?

Critics say soaring costs for disabled students means of

A growing population

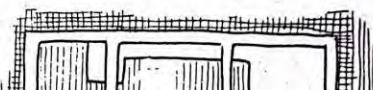
The number of special education students rises again. Increase of 4.2% is the largest since the Disabilities Act passed in 1976.

Total number of students	Change from previous year
1982-83	+0.5%

LETTERS TO THE EDITOR

Troublemakers in Public Schools

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



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.

But only one boy was expelled. The others were special education students, and federal law prohibits expulsion when the misbehavior results from a disability — even if students bring deadly weapons to school.

ST. LOUIS POST-DISPATCH

SATURDAY, MAY 3, 1997

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 Levin

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,

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 Committee on Economic and Educational Opportunity 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 and Gorton 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

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

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, and agreed to work together to try and stop and re-rewrite the bill together
- Drafted action alert that went out 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 on May 1 and Gang of 6 leaders also met with same request
- On May 2, Mr. Goodling agreed to a consensus group to try and come to agreement on a tight timeline. CCD met May 5 to discuss who would participate and Madeleine urged “big tent”

Parents Lead House Consensus Process

- House stopped action and allowed intense negotiations among groups. 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. Others came to the table when their issues come up. Discipline group met separately.
- 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.

Back to the Senate

- Sen. Lott replaced Sen. Dole as Majority Leader. Dole tried on his last day to get the Senate to pass the bill.
- Senate tried to get agreement on bill but Senators Ashcroft and Gorton refused.
- July 1996 Senators Frist and Harkin met with 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 for 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 where 1.) key R and D House and Senate staff and representatives from the Administration would “pre-negotiate” and draft a compromise bill and 2.) once a week, a meeting open to all disability and general and special education advocates would be held when decisions of the bipartisan working group would be reviewed and members would hear feedback from the field with Hoppe as a neutral facilitator. Work group discussions confidential. Deal was everyone 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. No reporters.
- 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.

Consensus!

- Senator Jeffords, Senate Committee Chair: “This legislation is the result of four months of intense discussion among Members of the committee, the House Committee and officials from the US Department of Education. The process followed in developing the legislation was unprecedented. The cooperation demonstrated by everyone was extraordinary.”

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.
- Sen. Gorton’s amendment would permit State and local education agencies to develop their own uniform discipline policies. Would have decimated IDEA civil rights protections. Vote crossed party lines: 48 yes, 54 no.
- Sen. Smith’s amendment would require courts, before awarding attorney’s fees to parents, to consider the financial impact that the award would have on the school district. Tabled 68 to 31.
- Consensus bill passed 98 to 1 on May 14, 1997.

IDEA 1997

- Access to, Participation in, and Progress in the General Curriculum
- Accountability: 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

IDEA 97 Enrollment Ceremony



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.
Photo by Kenneth Lambert/The Washington Times



TIP: Always say “thank you” and celebrate!



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.

IDEA 97 Bill Signing



President Clinton with Dave & Greg Hoppe
and Members of Congress

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.

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

- Testified before House Education & Workforce Committee

NDAC Members at 2017 NDSC Convention Advocate to Save Medicaid



TIP: Sometimes we stop bad things from happening and sometimes we make improvements possible!

MasonLIFE Capitol Hill Interns with Cong. Gregg Harper



**TIP: Self-advocates are the most
important advocates!**



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