FORUM

Ohio Coalition for the Education
of Children with Disabilities

September/October 2004
Volume XXII, Issue 3

IDEA Reauthorization Possible by Year–End

IDEA reauthorization may be moving again in Congress. The law (P.L. 105-17) first went into effect in 1975. This federal legislation protects the rights of children with disabilities and is a civil rights law in addition to being an education requirement.

Both the U.S. House and Senate have passed their respective versions of the measure and are awaiting a Conference Report.

The Senate appointed their conferees in September. Senator Mike DeWine (R-Ohio) is a member of this committee.

On October 8, Conference Committee members from the House were appointed, with the hope that their work would be finished so that President Bush can sign the law before the end of the year.

"I believe the President will have the chance to sign legislation before the end of 2004 that will support special education teachers and improve academic results for children with disabilities," said Education & the Workforce Committee Chairman John Boehner (R-OH). "I look forward to working with Democrats and Republicans in the coming weeks to ensure this happens."

The Senate bill maintains a requirement in the law that school officials must consider whether a disciplinary incident was a result of a student's disability. The House bill requires no such determination.

The Senate version requires higher teacher qualifications, and emphasizes procedural safeguards, and maintains basic FAPE (free, appropriate public education) requirements, while the House bill does not. The House bill would allow ten states to apply for a waiver to reduce paperwork. In April 2003, the House passed special education reform legislation (H.R. 1350) that would refocus the IDEA to improve education results for students with disabilities and reduce the paperwork burden on special education teachers. That bill, which received bipartisan support, has been hailed by school administrators as "the best special education policy revisions we've seen in decades."

If the Conference Committee meets, comes to agreement, and both the House and Senate agree before December 31, 2004, IDEA will be reauthorized. If not, the current law will be maintained and the whole process begins again after January 1, 2005.

Autism Increasing; OCALI Provides Services

There has been a tremendous growth in the numbers of students diagnosed with autism spectrum disorder during the past 20 years. To put this in perspective, the incidence has increased over 5000% during this period. According to the U.S. Department of Education figures, the number of students identified with autism in Ohio in 1992-93 was 22. In 2000-01, that number had risen to 2,217. The child count figures for 2003 in Ohio rose to 5,146. In 1996, the Centers for Disease Control and Prevention reported that autism occurred in 6.7 of every 1,000 children ages 3-10 years, based on the Brick Township Study. Recent estimates put the rate of autism incidence at one in 250 births.

With the increase in the numbers of children identified on the autism spectrum, the level of concern among parents about public schools adequately meeting the needs of students with autism has increased. This concern precipitated the creation of the Autism Scholarship Program in 2003 by the Ohio legislature to give parents choice regarding access to educational services outside the public schools.

The Ohio Department of Education established the Ohio Center for Autism and Low Incidence (OCALI) to provide information, resources, training and technical assistance to families and school districts to improve the education of students on the autism spectrum. OCALI has proposed the following four-year plan for development of the full menu of services and supports expected of a statewide center of excellence.

Year 1: Planning and Initial Resource Assessment. Becoming an Autism Clearinghouse.

Year 2: Implementation. Coordinating and collaborating with other agencies and organizations providing services to individuals with autism.

Year 3: Services Assessment and Expansion. Providing leadership and support for expanding existing services.

Year 4: Planning, Implementation and Technical Assistance. Initiating Ohio-based educational research.

OCALI will also:

* create a library of videos, books and other media available for loan;

* create a website that provides online resources, including original webcasts on relevant topics, fact sheets and articles, as well as links to other online resources;

* organize professional development activities and topical conferences for teachers, parents, related service personnel, and administrators incorporating the latest research and evidence-based practice;

* provide technical assistance to districts and families on program development and topical issues;

* provide leadership for the expansion and replication of existing program models and the creation of new models to meet the educational needs of Ohio students; and,

* continue focus on low incidence in the areas of autism, deaf-blindness, deafness and hearing impairments, multiple disabilities, orthopedic impairments, other health impairments, traumatic brain injuries, visual impairments, assistive technology, materials for students with visual impairments, Ohio's Assistive Technology Distance Learning Project (OATDLP), and other special projects.

The Case Against "Special Needs"

Words simultaneously reflect and reinforce our attitudes and perceptions; words shape our world. Many "disability labels" evoke feelings and imagery that perpetuate archaic and negative stereotypical perceptions. In turn, these perceptions create a powerful attitudinal barrier, which is the greatest obstacle to the success and inclusion of individuals who have been labeled.

Using People First Language (PFL) is a step in the right direction. For example, using PFL, we put the person before the disability and use more respectful terminology as in, "He has a cognitive disability," instead of, "He's retarded." (Visit www.disabilityisnatural.com to download the PFL article.) Many of us are consigning stigma-laden personal descriptors to the junk heap, such as "high (or "low") functioning," "developmental age," "wheelchair bound," and others. But one term—"special needs"—continues to be embraced by many. Because this descriptor is so commonly used, we seldom consider what message it sends or what image it evokes.

"Special needs" is a loaded descriptor that has done nothing to improve perceptions and everything to reinforce negative images. As a parent, I once used this term to describe my son when he was very young. Why not? That's what I heard coming out of the mouths of many: other parents, as well as therapists, educators, and others. But I stopped saying this years ago when I realized it's a descriptor that generates pity. Tell a new acquaintance, "My child has 'special needs'." The response is predictable: a sad, "Ohhh..." accompanied by a sympathetic pat on the arm. Worse, some even add, "I'm so sorry..." And this conversation often takes place in front of the child! What must it feel like to be the object of pity, especially when it's generated by the words of your own parent or someone else who professes to care about you?

Adults with developmental disabilities are our greatest teachers. I've never met one who likes "special needs." They vehemently describe disliking the "special" label as children, and they absolutely detest it as adults.

When I share this information during presentations, many parents defend their use of the term and add, "But don't all children have 'special needs'?" or "Aren't all children 'special'?" I might agree if the term had positive connotations and if we really meant "special." But it doesn't and we don't.

Once we use the "special needs" label, we stop thinking about an individual child and our ingrained assumptions take over. "Oh, yes, we know about those 'special needs' kids..." And at that point, we effectively rob a child of opportunities and put limits on her potential.

First, we've stripped her of the opportunity to define herself; what child can defend herself against the words and actions of her parents, teachers, and others? Second, we continue our robber baron ways by stealing opportunities for the child to lead a typical life. When applied to children and adults with disabilities, the "special" descriptor frequently---and almost automatically---leads to segregation! If we say a child has "special needs," then by extension, she must need "special (segregated) ed," "special" activities, and "special" environments. If she has "special needs" then she must not be "regular," and is therefore not entitled to participate in "regular" (typical) activities or live a Real Life. Too often, "special" has become a metaphor for "segregated."

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A parent may believe that her child can and should be included in school and the community. But if she uses "special needs" when describing her child to others, they may believe that inclusion isn't an option—-only a "special" environment will do. Labeling a child with the "special needs" descriptor puts her in a box—a box of our making, a box she never asked to be put into, and a box that limits hopes, dreams, high expectations, opportunities, and more. Many educators admit that they routinely have low expectations for children who are labeled with "special needs."

If our society believed children with "special needs" were really special, wouldn't every parent dream of having a "child with special needs?" But the opposite is true: our society so devalues children with disabilities that identifying and aborting them before they're even born is recommended by many health care professionals, and practiced by many parents. And within the adoption world, "special needs children" are often at the bottom of the list of "desirable children." So, again, just how special are children with "special needs?" Isn't the term actually a harmful euphemism which means just the opposite?

What do we really mean by "special needs" anyway? Like other disability descriptors, it may initially apply to one aspect of a person's life (a medical condition), but it quickly defines every aspect of a person like a terrible, dark shroud. Some people use the longer descriptor: "children with special health care needs." What makes one type of health care needs different or more "special" from another? Where, exactly, is the dividing line between "regular" health care needs and "special" health care needs? Who made this rule? Is this written somewhere? Do children with disabilities go to "special needs doctors" or "special needs hospitals?" I don't think so! During visits to my son's pediatric orthopedic physician, we saw children who had permanent physical disabilities and others with broken legs or arms. Does the child with a developmental disability have "special needs," but the child with a broken leg has "regular needs?"

If we use the "special health care needs" descriptor with legislators or policymakers, don't we need to explain what we really mean, or is the "special needs" imagery ("those poor, pitiful children") so deeply implanted in people's minds that it's assumed we know who and what we're talking about? A child might need a specific type of health care services, a wheelchair, or other types of support, accommodations, or assistive technology. And these may be different from the needs of a majority of children. But what makes these needs "special?" They're not "special" to the child. They are, in fact, perfectly ordinary needs for him. Calling my son's needs "special" because he needs a power wheelchair for effective mobility and I don't (at the present time) is an arrogant judgment call on my part.

What about the "special ed students" descriptor? In one school district's report on its "inclusive practices," the terms "special education students" or "special needs students" littered every page. The very use of these terms contradicted the thesis of the report: that students with disabilities were "included." Exclusion and marginalization always begin with the language we use and the mental images evoked by our words. In schools that are truly inclusive, students who receive special education services are "students," first.

Who really benefits from the "special needs" label? Certainly not the children or adults who have been labeled! They've been set apart and, thus, marginalized. Supporters of this descriptor can argue that saying "children with special needs" was necessary when advocating for certain laws, programs, or services. However, the same outcomes could have been achieved without the use of this pejorative term. In too many instances, we have chosen to use "special needs" in order to gain our objectives (because it evokes powerful emotions), but at what price to those who have been labeled?

"Special needs" is everywhere! The term is used by many organizations, it's on hundreds of websites, and it's one of the best terms for pulling at heartstrings! Want to raise money for your organization? Promote it as a fundraiser for "special needs kids," consider the imagery ("those poor, pitiful children"), and watch the dollars roll in. But again, at what price to the children who have been saddled with this sympathy-laden term?

Have we ever wondered how this descriptor might impact other children in the family? A brother might think, "If Mom says Katie is 'special,' what does that make me? Does Mom love her more?" The label can breed resentment and anger. But as the brother grows, he'll probably realize he doesn't want to be "special," especially if his "special" sister is marginalized, excluded, and pitied.

Far from being a compliment or an accurate term, "special needs" is a pejorative descriptor that creates a powerful attitudinal barrier to the inclusion of people who have been labeled. When using People First Language, we put the person first and also replace antiquated descriptors with words that are more respectful and accurate. But there is no singular replacement term for "special needs."

We can, however, use a variety of different descriptors, depending on the situation. In schools---and when it's appropriate—we can say "students who receive special ed services" (that's what it's supposed to be: services brought to the student, instead of making the student go to where the services are located). And we can use the generic, "children with disabilities" or the specific, "A child with (the name of the medical diagnosis)," when appropriate. But the use of any label should be restricted to specific times and places (at an IEP meeting, the doctor's office, etc.). Labels are, after all, simply medical diagnoses, and just as most of us don't share personal information such as medical diagnoses with every Tom, Dick, and Harry, we shouldn't be sharing the personal information of children and adults who have been labeled unless it's absolutely necessary, under certain circumstances, and with the permission of the person!

If we're serious about exploding disability myths and creating an inclusive society, do we dare set one group apart with the "special" descriptor? Shall we continue to perpetuate pity and marginalize people by using this label? Isn't it time to stop calling people names which they never chose to use about themselves? When we change our language, we change perceptions and attitudes. And when the Great Wall of attitudinal barriers falls, other barriers will also come tumbling down. Are the words you're using promoting a positive or negative image? Are they propping up the Great Wall of harmful perceptions or helping to tear it down?

Taken from The Disability is Natural Free Press, by Kathie Snow, Nov. 2003)

Better Mental Health Services Needed

A recent report from the United States House of Representatives Committee on Government Reform shows that failure to link mentally ill children with the services and treatments they need can carry heavy consequences. Two-thirds of the nation's juvenile-detention centers hold children and adolescents who are awaiting community mental-health treatment. In 33 states, the study found, such youngsters are incarcerated without any criminal charges, and those waiting for treatment are as young as age seven. Those centers spent over $100 million annually to house youths waiting for mental health services.

"Major improvements in community mental health services are urgently needed to prevent the unnecessary and inappropriate incarceration of children and youth in the U.S.," the report warns. The study was brought about by results of Senate hearings held last year to examine the challenges faced by families of mentally ill children.

In related developments, the Annenberg Public Policy Center at the University of Pennsylvania in Philadelphia released findings of a survey of high school "mental health professionals" which found that only 7% of these professionals said that all of their students who might need counseling or mental health treatment actually receive those services. 31% said that most of their students do receive services. 89% of respondents were school counselors, psychologists, social workers, or nurses. Only 34% of the high school staff members responding agreed that their schools had a "clearly defined and coordinated process for identifying students who may have a mental-health condition."

The National Association of School Psychologists said the study's findings should aid their groups' efforts to convince schools of the need for comprehensive mental-health services.

Web Site Supports "Our Kids"

Our-Kids Web site supports the ***Our-Kids*** Email list. ***Our-Kids*** is a "*Family*" of parents, caregivers and others who are working with children with physical and/or mental disabilities and delays. We call the list "***Our-Kids***". While it isn't exactingly descriptive, it avoids the pitfalls of labeling our kids anything but what they most certainly are: The wonderful little people in our lives.

The ***Our-Kids*** list consist of over 800 people representing children of varying diagnosis; everything from indefinite developmental delays and sensory integration problems, to cerebral palsy, to rare genetic disorders. Over 35 countries are represented on the list now. Our-Kids was formed in January 1993 by Ashley, on behalf of her son Austin who has Angelman Syndrome.

Here we can discuss our children's accomplishments and defeats, knowing that the audience includes others who know what we are going through. We can also get some idea of how others address specific problems/concerns with feeding, learning, schools, medical resources, techniques and equipment, as well as describing the problems to friends and family or just coping.

Michelangelo: Autistic Genius?

By Jeanie Lerche Davis,
WebMD Medical News

Classic tortured genius: The great artist Michelangelo may have suffered from autism, new research shows.

The report, which appears in the *Journal of Medical Biography*, provides a synthesis of new evidence about the famous 16th century artist, renowned for painting the Sistine Chapel in Rome.

"He was a loner, self-absorbed, and gave his undivided attention to his masterpieces -- a feature of autism," writes lead researcher Muhammad Arshad, PhD, a psychiatrist at Five Boroughs Partnership NHS Trust in Great Britain.

In his report, Arshad outlines research into the great artist -- taken from numerous works, including notes from the artist's assistant and his family. It all points to high-functioning autism, he says.

Autism is a complex disorder that does not affect intelligence. But it does impact how people perceive and process information. Difficulty communicating, social isolation, a need for control, and obsession with very specific interests are hallmarks of autism. For some people, all this makes daily functioning quite difficult. Others get along fairly well, even attend regular schools.

Michelangelo likely suffered from high-functioning autism, called Asperger's syndrome, says Arshad. Some of his evidence:

- The men in Michelangelo's family "displayed autistic traits" and mood disturbances. His family described him as "erratic" and "had trouble applying himself to anything." As a child and young man, he did not get along with his family and suffered physical abuse.

- The artist was aloof and a loner. The artist's mentor described Michelangelo as being unable to make friends or to maintain any relationship. He did not attend his brother's funeral, which underlined "his inability to show emotion," writes Arshad.

- He was obsessed with work and controlling everything in his life -- family, money, time. Loss of control caused him great frustration. He was able to generate, in a short time, many hundreds of sketches for the Sistine ceiling -- no two alike, nor any pose similar. He gave his undivided attention to his masterpieces.

- He had difficulty holding up his end of a conversation, often walking away in the middle of an exchange, writes Arshad. He had a short temper, a sarcastic wit, and was paranoid at times. He was bad-tempered and had angry outbursts.

- He rarely bathed, and often slept in his clothes including his boots. "He has sometimes gone so long without taking them off that then the skin came away, like a snake's, with the boots," wrote the artist's assistant.

(Taken from www.my.webmd.com/content/ article/87/ 99594.htm: May 26, 2004)

Program Helps College Students Find Jobs

When it comes to looking for a job, college seniors need all the help they can get. When that student has a disability, the task is that much more problematic. An important resource is The Workforce Recruitment Program for College Students with Disabilities. The program is co-sponsored by the Departments of Labor and Defense. One of the spearheading agencies is Labor's Office of Disability Employment Policy, headed by Dr. Roy Grizzard.

The overall objective of the recruitment program is to fund summer jobs to assist the transition from school to work for individuals with disabilities. Ultimately, agencies are encouraged to consider those summer hires for permanent employment and other career development opportunities.

Federal recruiters scour almost 200 colleges and universities each year. According to Grizzard, the program is now covering more schools with more resources than in 2003. And the additional effort is paying off. Grizzard attributes the increased success primarily to two factors. First, the number of participating colleges and universities has expanded since last year. More recruiters are covering more campuses. Second, "a lot more publicity and buy-in by federal employers," said Grizzard. More agencies accept the notion that employment candidates with disabilities are a tremendous resource and need to be mainstreamed into the whole employment process.

Dr. Grizzard also pointed out that this program exposes young college graduates with disabilities to meaningful work. Not menial administrative tasks, but work they can sink their teeth into and walk away "feeling they have made a significant contribution." The program also provides "an opportunity to develop a resume and to network."

FORUM is published by the Ohio Coalition for the Education of Children with Disabilities (OCECD), 165 West Center Street, Suite 302, Marion, Ohio 43302; telephone toll-free 800-374-2806 (Voice/TDD). Web site **www.ocecd.org**. E-mail **ocecd@gte.net**.

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Annual subscriptions are available for $10 for Consumers/Parents/Students; $20 for Professionals/Educators; $30 for Organizations.

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