



Policy Priorities
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I. Increasing Co-Sponsors For The Achieving A Better Life Experience (ABLE) Act

OBJECTIVE: The National Down Syndrome Society (NDSS), in conjunction with its affiliate partner DSANV, the coalition of organizations supporting The Achieving A Better Life Experience Act (ABLE), and key Members of Congress seek to have the legislation reintroduced and to increase co-sponsorship from newly elected Members of Congress. One strategy being developed is to incorporate the bill as part of any tax legislation passed by the 112th Congress.

SUMMARY: Through a partnership with DSANV, NDSS led a successful effort to reach consensus within the disability community, the Senate, and the House to introduce the ABLE bill, which allows for the creation of tax-advantaged disability savings accounts for individuals with Down syndrome, without jeopardizing benefits. A coalition of 40 organizations worked together to secure over 200 bipartisan co-sponsors in the House and Senate. The bill must now be reintroduced, previous co-sponsors must indicate they want to co-sponsor again, and the co-sponsorship of new Members of Congress must be sought.

The ABLE Act allowed individuals with disabilities and their families to save for expenses incurred across the lifespan such as education, housing and transportation. It also excluded assets in financial security accounts for individuals with disabilities in determining eligibility for Medicaid benefits, and for purposes of determining eligibility for certain means-tested federal programs.

KEY MESSAGES:

- In order to receive public benefits and support, adults with significant disabilities are not allowed to have assets of more than \$2,000. While these federal programs provide essential housing, employment and other support, they prevent individuals with significant disabilities from saving or earning more than a limited amount, resulting in impoverishment.
- Persons with disabilities should be encouraged and supported in their efforts to save in order to create an independent and meaningful life just as other Americans strive to do. ABLE helps to accomplish this goal by providing a vehicle for individuals and their families to save and build assets without jeopardizing the critical support programs provided by the federal, state and local governments.
- Establishing a savings instrument for individuals with disabilities and their families will provide them with the same flexibility, portability, and tax advantages that are available to all other Americans and their families.

BACKGROUND:

The legislation is built on the premise that persons with disabilities should be encouraged and supported in their efforts to save in order to create an independent and meaningful life just as other Americans strive to do. The ABLE legislation helps to accomplish this goal by providing a vehicle for individuals and their families to save and build assets without jeopardizing the critical support programs provided by federal, state and local governments. These critical programs are being constantly pushed to their limits, and these accounts are one method of helping to supplement them.

Parents and persons with disabilities face a stark and inequitable dilemma: either set aside the total amount of resources necessary to provide care and support for a person with a disability during that individual's entire lifetime or rely exclusively on public benefits. When a choice is made to rely on public benefits, the person with a disability is not permitted under Social Security regulations to accumulate more than \$2,000 in assets in his or her life, which means parents are not able to direct resources to the family member with a disability as they can to another child, and the child is not able to save the money he or she earns by working.

Features of the ABLE legislation are the following.

- **Allowable Expenses:** These include education, housing, employment support, health, prevention and wellness, and other life necessities as specified in the legislation.
- **Flexibility:** Setting up an account is as simple and inexpensive as opening a savings account. Rollover provisions are provided for families that currently have other types of accounts set up. ABLE accounts are created and regulated at the federal level so they operate under the same rules in every state. Contributions to the accounts can be made by any individual or entity including family, friends and employers.
- **Control:** Allows individuals with disabilities and their parents to choose to manage tax advantaged accounts and take responsibility for meeting reporting requirements as other Americans manage their savings accounts. In cases where the individual and/or parents determine that their management is not the appropriate course of action, an independent third party would be selected. This third party would be required to ascertain the wishes and desires of the individual with a disability before disbursing funds in accordance with those aspirations.
- **Benefit Protection:** Prohibits any federally funded program from considering amounts held or distributed from the account as income or assets when determining eligibility for benefits.

- **Tax Advantages:** Like college savings accounts (529 accounts) and Roth IRAs, funds held in ABLE accounts are contributed on an after-tax basis but grow tax free in a tax-exempt savings account. Withdrawals are not taxed as long as they are used to pay for qualified expenses.
- **Medicaid Payback:** At death or disqualification, funds are paid to the state from the ABLE accounts to the equivalent amount paid by a State Medicaid plan for total assistance.
- **Home Ownership:** The policy of preventing people with disabilities from holding assets is paradoxical and irrational. Family members with disabilities may be supported by their parents in the parental home, yet these parents cannot save funds and direct them to their child or adult with a disability. The person with a disability who receives public benefits may own a home, but he or she is not able to purchase one. Providing parents and persons with disabilities, a savings instrument that defers taxes would permit the accumulation of funds to purchase a home.
- **Education Funding:** Education of children and adults with disabilities often requires parents to incur additional expenses to accommodate their specific learning requirements, including tutors, assistive technology, universally designed (adapted) curriculum, digitalized texts and textbooks and other printed materials. In the past decade, as more post-secondary programs for students with intellectual disabilities have been created, parents have struggled to provide this type of support for their young adults with disabilities without the kind of tax-advantaged saving account that is available to parents of children without disabilities. While parents of children without disabilities may save funds for the education of their children using a 529 education account, parents of children with disabilities receiving Supplemental Security Income (Social Security benefits available to eligible persons with disabilities) are not able to utilize these education accounts.
- **Transportation and Employment Support:** The small amount of cash transfer payment that Social Security may provide to an individual with a disability, coupled with the small amount of income that he or she can earn, is not enough to cover transportation costs that may be necessary in order to work. Only when no public transportation alternative is available in a locality can an individual receiving Social Security deduct the cost of transportation from income earned. Otherwise, Social Security will not allow the individual to deduct the cost from income. For thousands of people with disabilities, the cost of transportation is prohibitive, and it means that they cannot join the workforce. If individuals with a disability were allowed to hold assets in an ABLE account, they could use the funds to cover their transportation costs.

- **Medical Support:** Many adults with disabilities do not have access to private medical insurance. Those who do work usually do not work for employers that offer medical coverage. Most are turned down by private insurance, and those who are accepted pay an average rate 38% higher than individuals without disabilities according to the 2003 Kaiser Family Foundation report, Medicaid's Role for People with Disabilities. ABLE account funds could be used to pay premiums on private and/or supplemental insurance coverage. The funds could also be used to cover gaps that exist in Medicaid and Medicare including long-term care and support services and equipment. The ABLE account allows for control of the funds by the individual or family. This means that they could decide which programs, coverage, and equipment they need rather than an outside entity.

II. **Securing Public And Private Funds To Ensure Physicians And Women Who Receive A Prenatal Diagnosis Receive Accurate, Up-To-Date Information**

OBJECTIVE: NDSS will target private funding sources and seek to work with the new Congress to secure funding for the implementation of the Kennedy-Brownback Act.

SUMMARY: NDSS spearheaded a successful effort to pass the Prenatally and Postnatally Diagnosed Conditions Awareness Act, otherwise known as the Kennedy-Brownback Act (named after the two Senate sponsors). The law, which passed in 2008, seeks to ensure that pregnant women receiving a positive prenatal test result and parents receiving a postnatal diagnosis will receive up-to-date, scientific information about life expectancy, clinical course, intellectual and functional development, and prenatal and postnatal treatment options. It offers referrals to support services such as hotlines, web sites, information clearinghouses, adoption registries, and parent support networks and programs specific to Down syndrome and other prenatally diagnosed conditions. The goal is to create a sensitive and coherent process for delivering information about the diagnosis across the spectrum of medical professionals and technicians, who often provide conflicting and inaccurate information.

In addition, through a generous donation from the Joseph P. Kennedy, Jr. Foundation, NDSS was able to focus efforts on the ever-changing landscape of prenatal testing and, more specifically, on the type and quality of educational materials regarding Down syndrome that are developed and marketed to medical professionals. Recently, NDSS awarded funds to Lettercase, a non-profit which developed *Understanding a Down Syndrome Diagnosis* with input and support from representatives of several medical organizations, NDSS, NDSC and the Kennedy Foundation Grant Advisory Committee, to print and distribute this prenatal booklet to members of the National Society of Genetic Counselors (NSGC), the American College of Medical Genetics (ACMG), and the American Congress of Obstetricians and Gynecologists (ACOG). Although this booklet will provide updated, accurate information to physicians and women who receive a prenatal diagnosis of Down syndrome, a critical challenge facing the entire Down syndrome community is securing funds to support an on-going process for developing updated versions of the Lettercase booklet in the future, with input from key members of the medical community, and funds for printing and dissemination of the Lettercase prenatal booklet nationwide.

KEY MESSAGES:

- The treatment options, functional development, opportunities and accomplishments of individuals with Down syndrome have improved dramatically over the years, yet decades old stereotypes still persist. It is critically important for healthcare professionals, families and society to update their knowledge and their perceptions about individuals with Down syndrome.
- \$5 million a year is the amount of funding that is necessary to allow the Department of Health and Human Services to: (1) collect and distribute information relating to Down syndrome and other prenatally or postnatally diagnosed conditions; (2) coordinate the provision of supportive services for patients receiving a positive diagnosis of a prenatally or postnatally diagnosed condition; and (3) oversee the new requirements for health care providers established by the law. The funding is also needed so that the Centers for Disease Control can assist state and local health departments in integrating testing results into surveillance systems.

BACKGROUND:

The Kennedy-Brownback legislation was enacted to increase patient referrals to providers of key support services for women who have received a positive diagnosis for Down syndrome, or other prenatally or postnatally diagnosed conditions, as well as to provide up-to-date information on the range of outcomes for individuals living with the diagnosed condition, including physical, developmental, educational, and psychosocial outcomes. The new law will strengthen existing networks of support and ensure that patients receive up-to-date, evidence-based information about the accuracy of the test. It was motivated by research conducted at Children's Hospital Boston (CHB).

A study by CHB researchers published in the March 2005 American Journal of Obstetrics and Gynecology (AJOG) found that obstetricians and genetic counselors provide too little information when it comes to delivering a prenatal diagnosis of Down syndrome to pregnant women.

"Mothers who have children with Down syndrome, diagnosed prenatally, reported that doctors did not tell them about the positive potential for people with Down syndrome, nor did they feel like they received enough up-to-date information or contact information for parent support groups," noted a CHB press release on the study following enactment of the Kennedy-Brownback legislation. "Further, the mothers reported that all of these shortcomings were happening at an emotional time when women have to decide whether or not to continue their pregnancies." This study was, and remains, the largest and most comprehensive study on prenatally diagnosed Down syndrome.

Based on this research, CHB researchers developed the following seven recommendations for communicating a diagnosis of Down syndrome:

- Results from the prenatal screening should be clearly explained as a risk assessment, not as a "positive" or "negative" result.

- Results from the amniocentesis or CVS should, whenever possible, be delivered in person, with both parents present.
- Sensitive language should be used when delivering a diagnosis of Down syndrome.
- If obstetricians rely on genetic counselors or other specialists to explain Down syndrome, sensitive, accurate, and consistent messages must be conveyed.
- Physicians should discuss all reasons for prenatal diagnosis including reassurance, advance awareness before delivery of the diagnosis of Down syndrome, adoption, as well as pregnancy termination.
- Up-to-date information on Down syndrome should be available.
- Contact with local Down syndrome support groups should be offered, if desired.

An article by CHB researchers published in the January 2005 issue of *Pediatrics* summarized responses from women who received the Down syndrome diagnosis postnatally. According to the article, physicians remain overwhelmingly negative in communicating the diagnosis of Down syndrome postnatally. Mothers reported that the majority of physicians were uninformed about the positive potential for children with Down syndrome and rarely provided an adequate, up-to-date description of children, printed information, or telephone numbers of other parents.

Approximately 5,000 children are born with Down syndrome each year. According to CHB researchers, of the mothers who receive the diagnosis, about 12.5 percent find out before birth, suggesting that 625 newborn infants with Down syndrome will be diagnosed prenatally each year. This number will only increase as new prenatal tests become available.

According to CHB, “All pregnant women are now offered prenatal testing for Down syndrome. Typically, although not necessarily, mothers will begin with a prenatal screening test like the triple screen, quadruple screen, or the newest combination of two maternal serum markers and ultrasonographic findings. With a 5 percent false-positive rate, 69 percent of fetuses with Down syndrome are correctly detected with triple screening, 81 percent with quadruple screening, and 87 percent with the recent first-trimester screening involving 2 maternal serum protein markers and ultrasonographic findings. For a definitive prenatal diagnosis, mothers have one of two options: chorionic villus sampling (CVS), typically between the 8th – 12th weeks of pregnancy or amniocentesis, typically after the 15th week of pregnancy. Neither procedure, however, is without risk; both carry an approximately 0.35 percent to 0.30 percent additional chance of causing a spontaneous miscarriage.”

III. Reintroducing And Increasing Co-sponsorship For The Trisomy 21 Translational Research Parity Act

OBJECTIVE: NDSS seeks to build political support for the enactment of the 21 Act by asking Members of Congress to reintroduce and to co-sponsor it.

SUMMARY: The Trisomy 21 Translational Research Parity Act of 2009 (21 Act) was introduced in the House of Representatives and the Senate during the last Congress. The bill aimed at expanding, intensifying and coordinating Down syndrome translational research across the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC) and other Federal agencies. The NDSS Policy Center, with critically important input from the NDSS Science Advisory Board and the Clinical Advisory Board, worked to develop this legislation with our partners on Capitol Hill. In addition, NDSS and other Down syndrome stakeholders have worked collaboratively with the Eunice Kennedy Shriver National Institute for Child Health and Development (NICHD) to begin developing a Down syndrome biobank and patient registry.

The 2009 bill now needs to be revised and be reintroduced, and co-sponsors need to be obtained. Features of the 2009 bill include:

- Creating at least six Down Syndrome Translational Research Centers of Excellence that provide an optimal venue and infrastructure for patient-oriented research, and conduct basic, clinical, and translational research on Down syndrome.
- Establishing a Down Syndrome Coordinating Committee to coordinate activities across NIH and with other Federal health programs and activities relating to Down syndrome.
- Calling for the development of a National Down Syndrome Patient Registry and Biobank, through cooperative agreements at CDC, to:
 - Provide clinical care for patients with Down syndrome;
 - Coordinate research and clinical activities through the Down Syndrome Translational Research Centers of Excellence with the activities of the National Down Syndrome Registry and Biobank; and
 - Create a common data entry and management system for Down syndrome patient data collection and analysis.

KEY MESSAGES:

- Down syndrome is the most frequent genetic cause of mild to moderate intellectual disabilities and associated medical problems, occurring in one out of 691 live births, in all races and socio-economic groups.
- The Children's Health Act (CHA) of 2000 addressed the research and surveillance needs of many disabilities, such as autism, traumatic brain injury, Fragile X, juvenile diabetes, asthma, epilepsy, and others. However, this landmark legislation did not address the significant research, surveillance, and clinical care needs of Down

syndrome and thus has been an impediment to progress in the Down syndrome research community over the last decade.

- This legislation will foster a better understanding of Down syndrome, and it will create and support avenues for translating the research results of clinical trials into actual therapies that can benefit those who have Down syndrome.

BACKGROUND:

Down syndrome, or Trisomy 21, as it is called within the medical community, is caused by an extra copy of the 21st chromosome. There are more than 400,000 people living with Down syndrome in the US. An error in cell division, called non-disjunction, happens at the moment of conception for reasons, which we still do not understand. The extra chromosome causes varying degrees of mental retardation and physical abnormalities.

Persons with Down syndrome can also have a wide range of health problems, including congenital heart defects, obstructed digestive systems, thyroid conditions, hearing problems, leukemia, increased susceptibility to infection, sleep apnea, and respiratory problems. Individuals with Down syndrome also are at a higher risk of developing Alzheimer's disease, autism, and many neurological and psychiatric disorders, including obsessive-compulsive disorder and depression.

The 21 Act would establish an infrastructure within the Department of Health and Human Services (HHS) to facilitate results-oriented research, forge new partnerships between academic institutions and clinics to work together to conduct translational research, produce targeted-funding opportunities, and help to develop new interventions, treatments, and therapeutics for Down syndrome.

Translational Research: The creation of Down Syndrome Centers of Excellence at the NIH would integrate basic and translational research and move findings efficiently toward clinical applications in Down syndrome. Research conducted on Down syndrome may also have spinoffs that increase knowledge about other areas of research, diseases, and conditions. Through outreach and communication efforts, the Centers will inform researchers and the public of scientific advances and improvements in medical care.

The CHA of 2000 (Public Law 106-310) amended the Public Health Service Act and included a number of provisions that addressed the research and surveillance needs of many disabilities (e.g. autism, traumatic brain injury, Fragile X, juvenile diabetes, asthma, epilepsy). However, this landmark legislation did not address the significant research, surveillance, and clinical care needs of Down syndrome and thus has been an impediment to progress in the Down syndrome research community over the last decade. The 21 Act attempts to incorporate Down syndrome as an area of permissible research and surveillance at NIH and CDC and will foster a better understanding of Down syndrome.

Coordination: The 21 Act would expand, intensify, and coordinate translational research on Down syndrome across government, academic institutions, Down syndrome clinics, and industry. Research and funding would be supported by administrative and program staff at the HHS and the individual NIH Institutes and Centers. The bill also calls for the establishment of a Down Syndrome Coordinating Committee, which includes Federal agencies and members of the public appointed by the HHS Secretary, to coordinate activities across Federal health programs and activities relating to Down syndrome.

Surveillance: The 21 Act would provide resources to build a National Down Syndrome Epidemiology program by constructing a National Down Syndrome Patient Registry and Biobank, through cooperative agreements at the CDC. The National Down Syndrome Patient Registry and Biobank would:

- Establish a centralized or distributed brain, cell, tissue, DNA, and RNA bank;
- Identify a cohort of patients for genotype-phenotype investigations to inter-operate with the bank; and
- Correlate the nature and severity of cognitive deficits and age of onset and severity of dementia.

This comprehensive surveillance program would enhance the clinical care for patients with Down syndrome, help coordinate research and clinical activities through the Down Syndrome Translational Research Centers of Excellence with the activities of the registry and biobank, and create a common data entry and management system for Down syndrome patient data collection and analysis.

IV. Maintaining The Current Level Of NIH Funding For Down Syndrome Research

OBJECTIVE: Obtain Congressional signatures on letter to NIH requesting that funding for Down syndrome research be held harmless.

SUMMARY: In January 2008, after consultation with the scientific research community and national organizations that focus on Down syndrome, and taking into account various congressional directives, the NIH Down Syndrome Working Group developed the NIH Research Plan for Down Syndrome. Because Congress does not earmark funds for specific diseases or conditions in its annual appropriations for NIH, efforts must be made to encourage NIH to fully fund the goals of the report, through research grant applications, public advocacy, and encouragement from Congress. Our long-term objective is to increase NIH funding for Down syndrome research; however, given the current economic climate and the Congressional focus on deficit reduction, the NDSS objective in 2011 is to prevent a cut in appropriations for Down syndrome research.

The purpose of the research plan is to build upon on-going NIH supported research to take advantage of emerging scientific opportunities and set the stage for possible future clinical trials in this area. The plan was a welcome development given the relatively small amount of funding that NIH currently dedicates, and has dedicated, to Down syndrome biomedical research. With sufficient resources, the plan has the potential to advance the translation and development of effective new treatments, particularly for cognition in Down syndrome. It will also encourage new therapeutic strategies involving secondary disorders affecting a significant numbers of individuals without Down syndrome, including Alzheimer's disease, atherosclerosis, cancer, and developmentally-associated cognitive impairment.

KEY MESSAGES:

- NDSS supports the recommendations of the NIH Research Plan on Down Syndrome, and appreciates the agency's stated commitment to improving the health of people with Down syndrome.
- NDSS believes that in the Fiscal Year 2012, NIH must retain the resources currently dedicated to Down syndrome research at the very least. In fact, NIH funding for Down syndrome research has decreased significantly over the past five years and, as the following chart indicates, such research continues to be disproportionately under-funded in relation to other conditions.

CONDITION	US POPULATION	NIH FUNDING (\$Millions)	NIH \$ PER CAPITA	RELATIVE FUNDING
Cystic Fibrosis	30,000	90	3,000	71.0X
Parkinson's	1,500,000	152	101	2.4X
ALS	30,000	43	1,433	34.1X
Huntington's	30,000	51	1,700	40.5X
Multiple Sclerosis	400,000	169	422	10.1X
Crohn's Disease	400,000	51	128	3.0X
Down Syndrome	400,000	17	42	1.0X
Fragile X	17,000	26	1,529	36.4X
Duchenne MD	45,350	22	485	11.5X
Autism	560,000	118	211	5.0X

BACKGROUND:

In 2006, the NIH established a Trans-NIH Task Force to develop a research plan to advance understanding of Down syndrome and speed development of new treatments for the condition. The Task Force was led by the National Institute of Child Health and Development (NICHD) and included representatives of the NIH Office of the Director and the Institutes of Cancer (NCI); Heart, Lung and Blood (NHLBI); Aging (NIA); Allergy and Infectious Diseases (NIAID); Mental Health (NIMH); Neurological Disorders and Stroke (NINDS); Deafness and other Communication Disorders (NIDCD); Drug Abuse (NIDA); and Dental and Craniofacial Research (NIDCR).

The task force held meetings with members of the scientific community and with representatives from national organizations, including NDSS. In 2007, NICHD placed a draft of the plan on its website for public comment, and released the final version on January 22, 2008.

The Research Plan on Down Syndrome sets research goals for the next 10 years that build upon earlier research advances fostered by the NIH. According to the members of the Trans-NIH Task Force, the research plan "is intended to provide the NIH, and its member Institutes and Centers, with guidelines for prioritizing and coordinating future research related to Down syndrome." According to NIH, the working group is moving

forward to implement plan objectives, and the short- term objectives are expected to be accomplished within the next three years.

The full research plan is available on the NICHD web site at http://www.nichd.nih.gov/publications/pubs/upload/NIH_Downsyntaxe_plan.pdf.

The following is the executive summary matrix of the report, which outlines the objectives of the NIH Research Plan on Down Syndrome:

Down Syndrome Research Area	Short term Objective (0-3 Years)	Mid term Objective (4-6 Years)	Long term Objective (7-10 Years)
Pathophysiology of Down Syndrome and Disease Progression	Continue testing cognitive and synaptic function In Down syndrome model mice.	Study whether the impact of aging on certain processes is greater than on others.	Explore genetic and environmental determinants of cognitive function in Down syndrome throughout the lifespan
Diagnosis, Screening, and Functional Measures	Identify the cognitive phenotype of Down syndrome in a cohort throughout the lifespan	Link human and mouse cognitive studies relating to Down syndrome.	Develop better measures of hippocampal and cognitive function
Treatment and Management	Increase research on co-morbid psychiatric and medical conditions throughout the lifespan	Continue learning from the Alzheimer disease research community regarding the best therapeutics	Investigate the impact of early intervention on psychomotor and cognitive development.
Living with Down Syndrome	Develop a more complete demographic knowledge base.	Study real-world outcomes for Down syndrome families.	Explore new intervention research, especially during transitional stages.
Research Infrastructure	Improve and expand availability of animal models	Discuss the best mechanisms to use in fostering cross-disciplinary research.	Include cohorts of people with Down syndrome in longitudinal studies

On September 23, 2009, Dr. Yvonne Maddox, the Deputy Director of NICHD, provided to the Congressional Down Syndrome Caucus a progress report on implementation of the Down Syndrome Research Plan.

To stimulate research among scientists in the Down syndrome research community, NICHD issued a Request for Applications (RFA) on “Factors Affecting Cognitive Function in Adults with Down Syndrome.” The funds were made available through the American Recovery and Reinvestment Act of 2009 (the so-called “Stimulus Act”), as well as existing grants and support for two-year research projects grants. NICHD made two program announcements; one focusing on family transitions, and the other focusing on associated conditions of adolescents with Down syndrome and health disparities. Program funding would provide research tools to scientists – including a repository for mouse models, and creating a brain and tissue bank – as well as training and mentoring of new investigators.

Recently, NICHD announced the approval of two new grants which will total over \$1 million a year over five years. One of the grants will go to the University of California Irvine to co-fund, with the NIA, research entitled “Predicting Cognitive Decline in Adults with Down Syndrome.” The second grant will go to the University of Louisville to co-fund, also with NIA, research entitled “Aging of Frontal Structure and Function in Down Syndrome and Dementia.”

According to Dr. Maddox, other Down syndrome research projects supported by the approximately \$1 million of Stimulus Act funding include:

- “Forebrain Development in Down Syndrome and in the Ts65Dn Model Mice” at Children’s National Medical Center in Washington, D.C.;
- “A Program of Research in Population Cytogenetics” at Washington State University; and
- “Cognitive Predictors of Language Impairment in Down Syndrome” at the University of Alabama.

The Down Syndrome Research Plan has, according to NICHD, resulted in expanded NIH efforts to enhance and support Down syndrome research, and an increase in the number of research grants submitted to NIH. However, with nearly 400,000 people with Down syndrome living in the United States today, this means that only \$40 is being committed in research dollars for each person with Down syndrome, far less than the amount of research funding allocated to far less common medical conditions. In addition, although NICHD approved two new grants using Stimulus Act funding, many more worthwhile research grant proposals were submitted and rejected. There are many wonderful researchers in the Down syndrome community, and there is no shortage of promising research projects which would help to meet the goals of the NIH strategic plan.

V. **Incorporating Universal Design For Learning (UDL) Provisions In Educational Legislation**

OBJECTIVE: NDSS seeks to provide meaningful access to the curriculum for ALL students, by incorporating provisions in Federal education legislation and policy that apply Universal Design For Learning (UDL) principles to all aspects of curriculum, including standards, instructional objectives, teaching methods, instructional materials and assessments. Target legislation includes the LEARN Act, the Elementary and Secondary Education Act (ESEA), formerly known as the No Child Left Behind Act, and any other education legislation proposed in 2011.

SUMMARY: The LEARN Act was introduced, but not passed, in the last Congress. This Act would authorize the Secretary of Education to award grants to states for comprehensive planning to improve the literacy of children from birth through grade 12. UDL provisions were included in both the House and Senate versions of the bill. A goal is to incorporate the LEARN Act into the House and Senate ESEA reauthorization bills when they are introduced.

The ESEA established high standards and accountability for the learning of all children. However, it has been a constant struggle to maintain high expectations for students with disabilities. UDL will help states, districts and schools meet the requirements of ESEA while maintaining high standards and accountability for all students. The President has called for the ESEA to be reauthorized this year, but it is not clear if and when that will happen.

KEY MESSAGES:

- UDL provisions in the House and Senate versions of the LEARN Act should be retained and the UDL provisions recommended by the National UDL Task Force should be incorporated in the reauthorization of ESEA. Similar UDL provisions should be included in any other education bills that are being drafted.
- UDL principles and guidelines can help states, districts, schools and teachers make educational decisions, which will ensure that all students have equal access to the curriculum and opportunities for acceleration.
- UDL will help improve academic performance and accurate assessment for all students by reducing the barriers to success that currently exist in the design of curriculum, instruction and assessment.

BACKGROUND: UDL is a set of principles based on research in neuroscience that demonstrate how learning is most effective when students are given various ways to acquire information and knowledge, to demonstrate what they have learned and to be engaged. There are nine guidelines and 32 checkpoints that are based on the UDL

principles. These create an education framework to guide decisions related to standards, instructional objectives, teaching methods, instructional materials and assessments so that all students can achieve.

In 2006, NDSS brought together general education and disability organizations to promote UDL in federal legislation and policy. This coalition, the National UDL Task Force, is comprised of 41 national organizations representing the interests of families, educators, administrators, school boards and higher education institutions. In 2007, UDL provisions recommended by the Task Force were included in a House draft ESEA reauthorization bill. The National UDL Task Force has drafted updated recommendations for the ESEA reauthorization. It is not clear if the draft House ESEA bill from 2007, which contained UDL provisions, will be used as starting point for reauthorization or if the bill will be completely redrafted.

The Task Force successfully advocated incorporating UDL provisions related to teacher preparation and accessible instruction in colleges classes in the Higher Education Opportunity Act of 2008. In addition, UDL was described in U.S. Department of Education guidance as a recommended use of Recovery Act funds and was included in the Administration's Blueprint for ESEA Reform and in the National Educational Technology Plan.

In addition, in 2010 NDSS worked with its Maryland Governmental Affairs Committee (GAC) to pass a state UDL bill. This project has provided a legislative model for other states, which will be posted on the NDSS website.

VI. Seeking An Opportunity To Reintroduce Restraints And Seclusion Consensus Legislation

OBJECTIVE: NDSS and members of a broad coalition of organizations were able to see the Keeping All Students Safe legislation passed in the House of Representatives, but the bill failed to pass in the Senate. In 2011, NDSS is working with the coalition of organizations to revise the legislation in a way that is acceptable to all the key stakeholders. If reintroduction of a consensus bill appears possible, NDSS will actively participate in an effort to pass the bill.

SUMMARY: Reports from the National Disability Rights Network (NDRN), the Alliance to Prevent Restraint, Aversive Interventions, and Seclusion (APRAIS), the Council of Parent Attorneys and Advocates, Inc. (COPAA), and the Government Accountability Office (GAO) have revealed disturbing findings about the use of restraint and seclusion in our nation's schools. The data collected reveals that there have been hundreds of incidents of physical injury, psychological trauma and even death. The Hartford Courant, in an award-winning series of stories about the use of restraint and seclusion confirmed 142 deaths. Complaints from many organizations led to a hearing conducted by Chairman George Miller of the House Education and Labor Committee and the subsequent passage of legislation in the House of Representatives to prohibit the use of mechanical restraint, chemical restraint, physical restraint that restricts the flow of air to the lungs and any other aversive behavioral intervention that compromises health and safety. The House-passed bill provided resources for training and support of school personnel, data collection, promoted best practices to prevent the use of harmful restraint and seclusion and set minimum standards for the use of restraint or seclusion.

KEY MESSAGES:

- Reports show that many students have been injured or suffered trauma as a result of restraint and seclusion methods. Many states do not have any law or regulations regarding the use of restraint and seclusion in schools and only eight specifically prohibit restraint that restrict air flow. Legislation is needed that will outlaw the use of restraint and seclusion in schools unless the student's behavior poses an immediate danger of physical injury and less restrictive interventions would be ineffective.
- A substantial number of students with intellectual disabilities have been and continue to be subject to restraint and seclusion. In part because many students with disabilities are not able to communicate adequately or at all about what has occurred during the course of the school day, legislation is needed that will require immediate parental notification and a school debriefing after each incident of restraint or seclusion.
- Many schools surveyed have indicated they do not have the resources to train staff in positive behavior supports and to implement their use on a school wide basis. Legislation is needed to assist schools and local education agencies to provide comprehensive training of staff.

BACKGROUND:

In recent years, important national disability organizations and the GAO have revealed hundreds of examples of the use of harmful restraint and seclusion.

Some of the cases reported by the GAO are the following:

- A 14 year old boy was restrained face down because he would not be seated in class. The 230 lb. teacher sat on the 129 lb boy, restricting his air flow which resulted in the boy's death.
- A four year old girl with cerebral palsy and autism was restrained in a wooden chair with leather straps for being "uncooperative".
- Children with disabilities, some only six year old, were allegedly placed in strangleholds, tethered to ropes and prevented from using the bathroom until they urinated on themselves.

After conducting an extensive national survey, the NDRN found the following:

- An eight year old with Down syndrome and Attention Deficit Hyperactive Disorder was secluded in an isolated room alone, and was not allowed out of isolation during the entire school day. His desk and chair and school supplies were removed and he was forced to eat and work on the floor.
- The Protection and Advocacy agency in California opened an investigation after a report of a classroom aide dragging a nine year old with Down syndrome across the play yard. The student sustained a back injury and significant skin abrasions. The aide was fired but the school has no record of the incident.

The House-passed bill would have expanded the CHA prohibition on the use of harmful restraint and seclusion practices in some hospitals and residential facilities to our nation's schools. The bill directed the Secretary of Education to establish minimum standards that: (1) prohibit elementary and secondary school personnel from managing any student by using any mechanical or chemical restraint, physical restraint or escort that restricts breathing, or aversive behavioral intervention that compromises student health and safety; (2) prohibit such personnel from using physical restraint or seclusion, unless such measures are required to eliminate an imminent danger of physical injury to the student or others and certain precautions are taken; (3) require states and local educational agencies (LEAs) to ensure that a sufficient number of school personnel receive state-approved training and certification in first aid and certain safe and effective student management techniques; (4) prohibit physical restraint or seclusion from being written into a student's education plan, individual safety plan, behavioral plan, or individual education program as a planned intervention; and (5) require schools to establish procedures to notify parents in a timely manner if physical restraint or seclusion is imposed on their child.

VII. Encouraging the U.S. Department Of Education (DOE) To Expedite Financial Aid For Students With Intellectual Disabilities In Postsecondary Education

OBJECTIVE: Strongly encourage the U.S. Department of Education (DOE) to eliminate bureaucratic barriers to college program and student financial aid approval and to provide technical assistance on financial aid to families and colleges.

SUMMARY: NDSS spearheaded a successful effort to amend the Higher Education Opportunity Act (HEOA) to authorize model demonstration grants, a coordinating center, and to allow students with intellectual disabilities to obtain financial aid to participate in postsecondary education. Although the bill passed and was signed by the President in August, 2008, bureaucratic barriers have stalled program approval and information to colleges and families. Consequently, very few programs have been approved and most students and families are not able to access the financial aid that was authorized in 2008. It is time for Congress to put pressure on the DOE to move forward.

KEY MESSAGES:

- Congress is to be commended for amending the HEOA in 2008 to allow students with intellectual disabilities who are enrolled in approved postsecondary education programs to be eligible for federal financial aid grants and work study jobs. Once implemented, this will be a tremendous help for students and families in paying for these important education opportunities which lead to jobs and life in the community.
- Despite Congress' clear direction, the DOE is moving at a snail's pace in implementing the law passed in 2008. Colleges and universities must apply to have their programs approved before students can apply for student aid. Only a handful of programs have been approved. The Department needs to speed up the program approval process and provide written technical assistance for colleges and universities and for families, who do not know how to fill out the financial aid (FAFSA) form for students with intellectual disabilities.

BACKGROUND:

Through generous grants from the Riggio family and the Taishoff Foundation, NDSS is the leading national advocacy organization on behalf of improving postsecondary education opportunities for students with intellectual disabilities. The NDSS Transition and Postsecondary Education Initiative has led to improved public policy, increased public awareness, the development of model programs and successful state-level systems change and technical assistance for colleges, universities, school systems and families. Along with George Mason University, NDSS sponsored the 2010 National State of the Art Conference on Postsecondary Education and Individuals with Intellectual Disabilities and plans are underway for the 2011 conference.

NDSS spearheaded a successful effort to amend the HEOA to authorize funding to develop high-quality, inclusive model comprehensive transition and post-secondary programs and a coordinating center for the new model programs. NDSS also led the

advocacy effort that resulted in \$11 million in appropriations for the model demonstration programs and coordinating center. Grants have been awarded to fund 27 two- and four-year institutions of higher education or consortia of institutions under the model comprehensive Transition Programs for Students with Intellectual Disabilities (TPSID).

The other key amendment included in the HEOA will allow students with intellectual disabilities who are enrolled in approved postsecondary education programs to be eligible for work study jobs, Federal Supplemental Educational Opportunity Grants and Pell Grants. NDSS served on a negotiated rulemaking committee that worked on developing implementing regulations. The Department used the negotiated rules as a basis for proposed and then final regulations. Although the law passed in 2008 and regulations were finalized on October 29, 2009, only a handful of programs have been approved. This delay is causing financial hardship for students with intellectual disabilities and their families.

VIII. Supporting The Transition Toward Excellence In Achievement And Mobility Act (TEAM ACT— To Be Introduced In 2011)

OBJECTIVE: NDSS is seeking to increase the number of co-sponsors of the TEAM Act which will be introduced by Congressman Gregg Harper (R-MS). This comprehensive legislation, which the NDSS Policy Center helped design, will improve the transition of youth with significant disabilities into integrated and competitive employment, training, career prep and post-secondary education.

SUMMARY: The TEAM Act is in the process of being finalized. It will focus, at a minimum, on strengthening the existing Individualized Education Plan (IEP) process in the educational system to ensure greater focus on desired transition outcomes through capacity building. It will require the use of evidence-based best practices to ensure successful transition planning, services and outcomes for youth with significant disabilities. The legislation will enable students with significant disabilities transitioning from school to become employed and earn at least minimum wage or to attend an appropriate post-secondary program. Strategies utilized to achieve these outcomes may include: inclusion in general education elementary and secondary classes with supports and services; school-based preparatory experiences, career preparation and work-based learning experiences, youth development and leadership, self-advocacy training and self-determination skill building and peer mentoring.

KEY MESSAGES:

- The unemployment statistics for people with disabilities, particularly people with intellectual disabilities, have remained stubbornly high. This is due in large part to public policy which actually discourages them from working. Moreover, the extremely low amount of assets and income which are permissible for people with disabilities who receive public benefits keep them in poverty. The legislation would authorize funds to state grantees as part of a systems change initiative to target and support students exiting schools so they become employed and earn at least minimum wage. It makes no sense to keep people with Down syndrome and other disabilities dependent on society when they want to work and can work.
- Over 460,000 individuals with significant disabilities are in sheltered workshops and earning less than minimum wage or in day programs where they earn no wages. Despite advances in education, medicine and other improvements in the lives of people with Ds, too many of them do not have the opportunity to participate in the workforce. They are not able to make choices about the use of funds they are eligible to receive for long term supports and services. This legislation would promote the use of a range of best practices such as support for having a job while still in secondary school.

BACKGROUND:

The current draft outline of key parts of the legislative proposal includes the following:

- Focus on strengthening existing IEP process in the educational system to ensure greater focus on desired transition outcomes: enhance and improve current transition strategies and practices through the IEP process for youth with significant disabilities eligible for DD Services currently in the educational system.
- Focus on creating an effective person-centered, individualized transition process for young adults transitioning from secondary education into the adult services system.

IX. Modernizing Existing Laws That Contain Barriers To Employment

OBJECTIVE: The Collaboration to Promote Self-Determination (CPSD), which NDSS co-founded with the National Fragile X Foundation and the Autism Society of America, has focused for the past several years on taking a comprehensive approach to modernizing programs that aim to assist individuals in finding and maintaining employment and independent living. In 2011, CPSD will advocate for the implementation of an Employment First policy agenda at the federal level through legislative and regulatory changes. This work will include establishing in law that employment is the preferred outcome for all citizens with intellectual disabilities and that systems should have statutory responsibilities to align their policies, processes and reimbursement practices to incentivize and fund services that lead to the preferred outcome. Additionally, the CPSD will strongly advocate for: the passage of the TEAM Act which will improve the process of transition to employment and post-secondary education; the passage of the ABLE Act which will allow individuals with disabilities and their family to save assets without jeopardizing access to publicly funded resources; and the passage of legislation introduced by Senator Tom Harkin (D-IA) in 2011 that will promote employment at minimum wage or better.

SUMMARY: Launched in 2007, the CPSD advocacy network of twelve national disability organizations and forty national advisors is committed to ensuring that every adult aged 18 or older living with intellectual and developmental disabilities should be encouraged and empowered to lead an independent, productive life through self-direction and self-determination. The CPSD has found a champion with whom to partner in Congressman Gregg Harper (R-MS) who, in early 2011, will introduce the TEAM Act which will improve the transition process and, as students exit education, help them find employment as quickly as possible.

KEY MESSAGES:

- There are over 190 uncoordinated programs across 23 departments of the federal government that exist, according to a GAO study, to provide assistance to persons with disabilities, including persons with intellectual disabilities. These programs lead to employment and independent living for only a small portion of the population of persons with intellectual disabilities. In fact, these programs, many decades old, are badly in need of modernization built on a new framework that promotes earnings and savings, and establishes employment as the preferred outcome of federal assistance. The current disability framework is based on the premise that individuals with significant disabilities must not have assets of more than \$2,000 and must be restricted to very low wages. The ultimate result is pervasive and unacceptably high unemployment and poverty.
- A new disability framework must also incorporate the concept of self-determination based on self-directed planning centered on the individual. It is especially important for the person with a disability and the person's family to be able to plan for the

future and to direct public resources which the individual receives to achieve the desired goals of employment and independent living. A key means of exercising self-determination would involve allowing families and their member with a disability to develop an individual budget to be used to implement the individual's own plan to attain as much self-sufficiency as possible.

- Congress and the Administration should embrace the creation of a comprehensive strategy to modernize federal programs for individuals with disabilities. Congress should create a special Study Group which would bring together staff from key congressional committees that have oversight for disability programs to align laws and regulations to produce effective coordination of services and blending of resources. Similarly, the federal government should implement a recommendation made by the GAO to assign responsibility to a government entity to develop common definitions, outcomes and performance measures across disability programs.

BACKGROUND:

For three years, the twelve organizations that make up CPSD have labored to aggressively campaign for major modernization of federal programs that are designed to aid people with disabilities and their families. This campaign has taken many forms and involved many activities. The most important milestones of the CPSD are the following:

- Organized and co-hosted a National Roundtable on Supported Employment with the U.S. Department of Labor's Office of Disability Employment Policy in October 2008.
- Supported passage of the ABLE Act in the 110th-112th Congresses.
- Crafted policy recommendations for the reauthorization of the Workforce Investment Act & Rehabilitation Act that will result in improved integrated employment outcomes for citizens with significant disabilities, including a systematic reduction in the use of segregated employment and subminimum wage.
- Provided recommendations to Centers for Medicaid Services (CMS) on improvements related to the Home and Community Based Care (HCBS) Waiver and State Plan Amendment processes so as to ensure a more focused concentration of public resources on outcomes that promote integrated employment and community living among citizens with significant disabilities.
- Created ongoing dialogue with six federal partners including the Administration on Developmental Disabilities, Centers for Medicare and Medicaid Services, Office of Special Education & Rehabilitative Services.
- Developed a series of legislation introduced on February 8th of 2011 to ensure a comprehensive, cross-agency commitment to improve the outcomes of youth with significant disabilities transitioning into adulthood.