# National Disability Policy: A Progress Report



National Council on Disability September 18,2012

National Council on Disability 1331 F Street, NW, Suite 850 Washington, DC 20004

#### National Disability Policy: A Progress Report

This report is also available in alternative formats and on the National Council on Disability (NCD) Web site (www.ncd.gov).

September 18, 2012

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The views contained in this report do not necessarily represent those of the Administration, as this and all NCD documents are not subject to the A-19 Executive Branch review process.



An independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families.

# Letter of Transmittal

September 18, 2012

The President The White House Washington, DC 20500

Dear Mr. President:

The National Council on Disability (NCD) is charged with developing an annual report on the nation's progress in achieving our national disability policy goals: equality of opportunity, independent living, full participation and economic self-sufficiency for an estimated 54 million Americans with disabilities. This is a daunting task. Virtually every foreign and domestic policy issue has—or should have—a disability angle. Our engagements in military conflicts, overseas diplomatic efforts, budget decisions, infrastructure development, enforcement activities, education, health care, employment, transportation, telecommunications, and emergency preparedness policies all have direct and indirect impacts on Americans with disabilities—irrespective of whether decision-makers are aware the far-reaching effects of their daily decisions on people with disabilities.

NCD's *National Disability Policy: A Progress Report* fulfills our mandate by highlighting recent achievements that show significant progress on disability policy and identifying areas where action is acutely needed. As charged by statute, this report serves not merely as a report on NCD's efforts or even of the federal government, but rather on significant developments across the nation. While the report focuses on the period between September 2011 and June 2012, we also seek to contextualize recent developments to illustrate progress and how progress is often agonizingly elusive. The material in this report is based on our engagement with stakeholders, actions among federal agencies and Congress, and NCD's own policy projects.

With last year's report, NCD began identifying and evaluating national data sets as a tool to assess progress with more precision and enable tracking over time. Unfortunately, there are few updates to those data sets available today. With this year's report, NCD provides a high-level, interim policy assessment under the thematic organizing framework NCD adopted in *2010: Living, Learning and Earning*. NCD adopted these three themes to emphasize that people with disabilities want what all Americans want: to live free and full lives in communities of their choosing, to learn in

1331 F Street, NW ■ Suite 850 ■ Washington, DC 20004 202-272-2004 Voice ■ 202-272-2074 TTY ■ 202-272-2022 Fax ■ www.ncd.gov ways that enrich their lives and enable them to reach their potential, and to provide for themselves and their families.

A central theme in this report is NCD's conviction that achieving long-term fiscal stability requires eliminating outdated and costly policies that trap Americans with disabilities in cycles of poverty and dependency, and cultivating meaningful opportunities for these and all Americans to contribute to our nation's collective well-being. This effort depends on finding ways to integrate and coordinate the delivery of necessary supports and services across federal departments, agencies, programs and policies. Unfortunately, lack of authority and lack of focused effort often conspire to perpetuate fragmentation and prevent real progress. This report seeks to identify some of the important progress and challenges in coordinating disability policy and promoting the independence and self-sufficiency of Americans with disabilities.

NCD has appreciated the opportunity to work with your Administration and Congress in furthering the goals of the ADA. We are pleased to report that we are making progress, yet sobered by the magnitude of the tasks that lie ahead. While we recognize that there are extreme pressures to curtail the federal budget, we hope your Administration and the Congress will join us in recognizing we must continue to expand opportunities for people with disabilities to contribute to their fullest potential. Failure to do so not only jeopardizes the lives of people with disabilities; it also threatens our national recovery. NCD is a tiny agency with a huge mission, but we are ready to do our part in helping to make the promises of the ADA a reality.

Sincerely,

Jonathan M. Young Chairman

(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate and the Speaker of the House of Representatives.)

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# **Report Introduction**

This annual progress report by the National Council on Disability (NCD) provides a glimpse at the current state of people with disabilities in the United States. This report covers the period of summer 2011 through spring 2012 by issue area, and reviews top-level policy developments affecting people with disabilities, including key federal actions and state trends. The report notes progress where it has occurred and provides further recommendations where necessary. The material in this report comes from NCD stakeholders, federal agencies, and information gathered during NCD policy projects.

The report is organized into three chapters based on the broad policy themes by which NCD has organized its work since the summer of 2010—living, learning, and earning— the thought behind which is that all people, including people with disabilities, have the same fundamental wants and needs—to live, to learn, and to earn. Woven throughout each themed chapter is an examination of the impact of the current recession and slow recovery on the lives of people with disabilities, and the unique as well as shared experiences facing military service members and veterans of all wars. Each chapter also contains several lists of recommendations for specific actions, primarily for Congress and the Administration. Many of these recommendations emphasize enforcement of existing laws, as well as revisions to policies and practices intended to improve living, learning, and earning opportunities for people with disabilities.

In Chapter One: Community Living, NCD examines to what extent people with disabilities are included in all aspects of community living—including housing, health care, emergency management, raising families, and transportation. In Chapter Two: Learning, NCD begins to consider the impacts of education reforms on students with disabilities; the effect of No Child Left Behind (NCLB) waivers now and in the future; bullying prevention; and the elimination of aversives, seclusion, and restraints. In Chapter Three: Earning, NCD considers the reauthorization of the Workforce

Investment Act; employment disparities among subgroups of people with disabilities; and unemployment gaps among people with and without disabilities.

# CHAPTER 1. Community Living

# Introduction

Satisfaction with community living depends on having personal choices, access to places and information, and the safety and freedom to fully participate in community life. As millions of people with disabilities know, failure to coordinate various elements of inclusion means missing out on opportunities to live, learn, and earn in the United States of America. Successful community living occurs when people have independence, safety and security, freedom of mobility, freedom of communication, affordable and accessible housing and transportation, and access to health care and long-term services and supports. It occurs when citizens with disabilities are involved in all aspects of community planning and implementation, including emergency preparedness.

# Americans with Disabilities Act (and Amendments)

#### ADA Standards for Accessible Design

On March 15, 2012, the U.S. Department of Justice (DOJ) announced that regulations based on revised 2010 Americans with Disabilities Act (ADA) Standards for Accessible Design had gone into effect.<sup>1</sup> The 2010 Standards, which underwent extensive review and numerous open comment periods over more than 10 years, set requirements for built-in elements at public facilities, including but not limited to courtrooms and detention facilities, amusement rides, and swimming pools and play areas. The Standards also clarify requirements for accessible and companion seating at stadiums and other assembly areas, distribution of accessible hotel rooms among different classes of hotel rooms provided, overlap between wheelchair accessible rooms and rooms with communication features, and reach ranges and toilet room dimensions. The new

Standards have been widely heralded by people with disabilities as a significant step toward realizing the promises of the ADA.

However, the continued challenges in realizing the promises of the ADA were also evident in a controversy surrounding one element of the new Standards: the requirement that owners and operators of public swimming pools must acquire and maintain bolted-down mechanical chair lifts. Although the proposed requirements were long in the making, announced in 2010 with compliance scheduled originally for March 15. 2012.<sup>2</sup> and despite the fact that DOJ provided what appeared to be sufficient clarification to the proposed swimming pool regulations, owners and operators objected to the proposed rule before it went into effect. Initially, DOJ extended the deadline for compliance to May 21, 2012, to respond to this objection. This action raised concerns among disability advocates that swimming pool owners and operators would seek to set aside the new requirement. Indeed, measures were introduced in Congress that would substantially modify the proposed requirement.<sup>3</sup> However, on May 24, 2012, DOJ released two technical assistance documents as part of its effort to continue to educate covered entities about their obligations under the 2010 Standards. DOJ also announced that the final rule would go into effect with no change to its requirements, but with an additional extension for compliance to January 31, 2013.<sup>4</sup>

#### **Project Civic Access**

Launched in August 1999, Project Civic Access is a DOJ initiative to remove barriers across local governments. In 2011, the Disability Rights Section of DOJ's Civil Rights Division reached settlement agreements across the United States to ensure compliance with the ADA. DOJ also developed technical assistance materials on Title II and Title III of the ADA, including accessible entry and exit requirements for swimming pools and spas, revised ADA requirements on ticket sales, and revised ADA requirements regarding service animals, to assist other localities in reaching this goal. Title II of the ADA specifically prohibits discrimination on the basis of disability by public entities. From June 28, 2011, through February 8, 2012, the following municipalities reached agreements with DOJ to meet the requirements of the ADA by removing physical and communication barriers that prevent people with disabilities from participating fully in civic life in their communities:

- February 8, 2012 Humboldt, Kansas, agreed to make physical modifications to facilities, improve access to sidewalks, upgrade the telephone relay service, post notices, improve Web access, and ensure emergency management services, among other improvements.
- November 22, 2011 Upshur County, Texas, agreed to appoint an ADA coordinator, make physical modifications to facilities, improve sidewalk access, post notices, improve Web access, and ensure emergency management services, among other improvements.
- September 28, 2011 Warrenton, Virginia, agreed to survey facilities and programs to ensure ADA compliance, make physical modifications to facilities, improve access to sidewalks, install signs, and improve Web access, among other improvements.
- August 29, 2011 The Puerto Rico Department of Justice agreed to pay \$45,000 to an employee denied a reasonable accommodation. It also agreed to provide training to employees on the requirements of the ADA, and adopt policies to ensure that it does not require employees with disabilities to attend meetings at, or be relocated to, an inaccessible location.
- August 16, 2011 The Maryland National Capital Park and Planning Commission and Montgomery County, Maryland, agreed to a wide-ranging series of accommodations to improve access for people with disabilities.

- July 26, 2011 Madison, Indiana, Daviess County, Kentucky, and Norfolk County, Massachusetts, agreed to make physical modifications to public facilities and improve access to parking, entrances, assembly areas, and restrooms.
  Improvements in effective communication (e.g., Web site and telephone communications), grievance procedures, polling places, emergency management procedures and policies, and sidewalks were also agreed on.
- June 28, 2011 Van Buren County, Arkansas, agreed to improve the accessibility of sidewalks, transportation stops, and pedestrian crossings; make physical modifications to facilities; improve access to sidewalks; upgrade the telephone relay service; post notices; improve Web access; and ensure emergency management services, among other improvements.

### **Other ADA Enforcement**

In addition to the enforcement activities of Project Civic Access, in the past year, DOJ and courts around the nation reached agreements or filed suit to ensure access for Americans with disabilities. These cases included the following:

- On March 30, 2012, DOJ announced a settlement with Trinity Regional Medical Center in Fort Dodge, Iowa, regarding allegations of a failure to provide appropriate auxiliary aids and services, including sign language interpreters, to patients who are deaf, resulting in confusion, a lack of understanding of medical instructions, and long waits. The settlement included a civil penalty, provision of training to hospital staff regarding the requirements of the ADA, and the adoption of policies and procedures to ensure prompt provision of auxiliary aids and services in the future for patients who are deaf or hard of hearing or their companions.<sup>5</sup>
- On March 20, 2012, DOJ announced a settlement with Mountain Valley, Pennsylvania, Midget Football League following allegations that the league

refused to allow a seven-year-old boy with ocular albinism to play football in the league with a helmet with a tinted visor as an accommodation. Conditions of the settlement include the requirement that the league develop and implement a disability rights policy, train league officials on the ADA requirements, and grant reasonable accommodations.<sup>6</sup>

- On February 1, 2012, DOJ announced a settlement with Henry Ford Health System in Ferndale, Michigan, regarding allegations of the system's failure to provide auxiliary aids and services to enable a patient who is deaf (and visiting family members who are deaf) at an inpatient psychiatric facility to communicate effectively with health care providers. The settlement requires staff training on ADA requirements; development and adoption of policies and procedures regarding the provision of auxiliary aids and services; and appointment of a corporate ADA administrator and ADA facilitators at each hospital, clinic, and health center.<sup>7</sup>
- On June 28, 2011, DOJ announced that it reached a settlement agreement with Beach Babies Learning Center, LLC, in Old Saybrook, Connecticut. The agreement resolves allegations the center terminated the enrollment of a twoyear-old child because the child has autism.<sup>8</sup>
- On June 24, 2011, a U.S. District Court jury in Fort Myers found that 7-Eleven violated the Florida Civil Rights Act and the ADA when it fired Jim Soliday, an employee who is deaf, after removing his accommodations.<sup>9</sup>
- On May 31, 2011, DOJ reached a settlement with Wells Fargo & Company to ensure equal access for individuals with disabilities to Wells Fargo's services nationwide, including its nearly 10,000 retail banking, brokerage, and mortgage stores; more than 12,000 ATMs; and telephone and Web site services.<sup>10</sup>

#### **Olmstead Enforcement**

Thirteen years ago, the U.S. Supreme Court ruled in *Olmstead v. L.C.* that Title II of the ADA prohibits the unnecessary institutionalization of people with disabilities. In the words of the Court, services to people with disabilities must be provided "in the most integrated setting possible." As states across the country continue to struggle with budget shortfalls, lawmakers have often contemplated or made cuts to services that have imperiled the ability of people with disabilities to remain in or transition to the most integrated setting possible. Actualizing the promise of the *Olmstead* decision has become a major component of ADA enforcement. To quote Assistant Attorney-General for Civil Rights Tom Perez, "Segregating people with disabilities into institutions is as wrong as segregating African-American children into inferior schools."<sup>11</sup>

Recent Olmstead decisions include the following:

- On April 12, 2012, DOJ filed a Statement of Interest in *Lane v. Kitzhaber,* asserting that "the integration regulation prohibits the unnecessary segregation of persons with disabilities by public entities in non-residential settings, including segregated sheltered workshops."<sup>12</sup>
- On January 26, 2012, DOJ concluded an *Olmstead* investigation in Virginia with an agreement that Virginia will create approximately 4,200 home- and community-based waivers over 10 years for people who are on waiting lists for community services or transitioning from institutional settings. Virginia also agreed to create a comprehensive community crisis system with a full range of crisis services, including a hotline, mobile crisis teams, and crisis stabilization programs, to divert individuals from unnecessary institutionalization or other out-of-home placements.<sup>13</sup>
- On January 9, 2012, DOJ filed a Statement of Interest regarding a plaintiffs' challenge to a 20 percent reduction in personal care services provided through California's In-Home Support Services (IHSS) program. IHSS is designed to

enable seniors and people with disabilities to avoid hospitalization and institutionalization.<sup>14</sup>

- In December 2011, DOJ issued a Findings Letter concluding that Mississippi is in violation of the ADA's integration mandate to provide meaningful opportunities for people with disabilities to live in most integrated community settings.<sup>15</sup>
- On July 12, 2011, DOJ filed an amicus brief supporting California adults with physical and mental disabilities, who argued that state policies place them at serious risk and are actionable under the ADA.<sup>16</sup>
- On July 6, 2011, DOJ announced that it had entered into a comprehensive agreement with Delaware to resolve violations of the ADA within the state's mental health system.<sup>17</sup>

#### Recommendations

NCD recommends:

- 1.1 The U.S. Department of Justice should enforce the Americans with Disabilities Act 2010 Standards for Accessible Design, including regulations regarding the accessibility of swimming pools, without further extensions.
- 1.2 DOJ should maintain and expand its efforts to ensure state compliance with the Supreme Court's *Olmstead v. L.C.,* focusing its efforts on the closure of institutions both large and small and advancing the ADA's integration mandate and the application of the *Olmstead* decision in other types of public programs, such as employment.

1.3 DOJ should consider mechanisms to expand its enforcement activities in the context of education, placing particular emphasis on strategic litigation aimed at addressing issues of segregation of students with disabilities in public schools, including charter schools.

#### **Developmental Disabilities Assistance and Bill of Rights Act (DD Act)**

In 1963, the U.S. Congress passed the Developmental Disabilities Assistance and Bill of Rights Act, which created an infrastructure of state developmental disability planning councils, the University Affiliated Centers (now known as Centers of Excellence), and the Protection and Advocacy system. Within these systems, much has been done to build both peer and family support programs. These programs have been very helpful, particularly in states that have closed institutions. This same type of support is important to create successful transitions from sheltered workshop settings to integrated competitive employment opportunities.

In 2011, NCD released *Rising Expectations: The Developmental Disabilities Act Revisited,* which summarized many of the key accomplishments and challenges of the DD system as well as considered the existing structure against a backdrop of the current and future social and policy environments.<sup>18</sup> In April 2012, NCD issued a supplement to the *Rising Expectations* report, titled *Exploring New Paradigms for the Developmental Disabilities Assistance and Bill of Rights Act,* which builds on the former report by exploring opportunities for the expansion of the DD network infrastructure to fully realize the goals of the DD Act and to establish a comprehensive policy framework of clear, consistent objectives across federal agencies and key laws.<sup>19</sup> The report makes pointed recommendations for addressing structural challenges to policy, program, and service coordination. These recommendations were formulated as a result of a comprehensive literature review of trends, developments, and challenges since the last DD Act reauthorization in 2000, as well as interviews and focus groups with individual stakeholders, including self-advocates, family advocates, researchers, practitioners, and state and Federal Government officials.

In *New Paradigms,* NCD recommends restructuring the Federal Government's response to disability policy to address and remove the administrative constraints on the Administration on Developmental Disabilities (ADD) as well as to facilitate more intuitive coordination of programs, services, and supports. Coincidentally, shortly before the release of *New Paradigms,* the U.S. Department of Health and Human Services (HHS) announced a structural reorganization that brings together several program offices that provide support for aging and disability communities under a newly created operating division called the Administration on Community Living.<sup>20</sup> NCD is heartened that this newly created division assists in repositioning and elevating ADD's status. However, coordination of services for populations with intellectual and developmental disabilities (ID/DD) that are provided outside of HHS will remain problematic until further shifts occur.

Most notably, the newly named Administration on Intellectual and Developmental Disabilities (AIDD, formerly ADD) continues to lack a direct policy and funding relationship with key stakeholders who have developed a presence in developmental disability policy over the past several decades. Although AIDD is the key federal agency within HHS charged with encouraging and supporting the provision of services to people with intellectual and developmental disabilities,<sup>21</sup> it possesses no funding or policy relationship with state ID/DD service-provision agencies, the primary entities responsible for administering services for people with ID/DD at the state level. As a result, AIDD is forced to pursue its systems change priorities indirectly, through influencing state DD Network partners, such as the Protection and Advocacy programs, or by working to influence the Center for Medicare and Medicaid Services. This lack of authority seriously hamstrings AIDD's effectiveness in advancing the goals and values of the DD Act.

NCD urges the creation of a direct relationship with state ID/DD agencies to enhance AIDD's ability to drive meaningful change. Such a relationship could take several forms. Although the Medicaid program is the largest source of funding for state ID/DD agencies, providing AIDD with a funding stream allocated specifically for systems

change grants to state ID/DD agencies would give AIDD valuable leverage to assist states interested in improving their service-delivery systems but requiring additional support to do so. Furthermore, a formula grant to state ID/DD agencies administered by AIDD and geared specifically at data collection activities would provide AIDD with valuable leverage to establish and hold states accountable for clear metrics and outcome measures reflecting the values of the DD Act.

Another key gap within the present DD Act programs remains the absence of a statutorily defined mechanism for AIDD to support self-advocacy organizations-defined as organizations run by people with intellectual and developmental disabilities speaking on their own behalf and on behalf of their communities. At the time Congress created the DD Act programs, the primary stakeholders within the developmental disability world were family members, researchers, and legal advocates. The current DD Act programs reflect this in their establishment of a University Center of Excellence on Developmental Disability, Protection and Advocacy system, and state Developmental Disability Planning Council within each state. However, the past several decades have seen the emergence of a new stakeholder group deserving of representation within the DD Act: people with intellectual and developmental disabilities themselves. Although the self-advocacy movement-defined as people with disabilities working to advance their community's interests and speaking on their own behalf—is not yet sufficiently developed to allow the creation of a federally funded statewide entity within each state akin to the other DD Network partners, it is nonetheless capable and deserving of federal support and investment. Self-advocacy organizations have played a key role in driving systems change and connecting individuals with intellectual and developmental disabilities to meaningful resources regarding topics as diverse as benefits planning, relationships and sexuality, housing, deinstitutionalization, social inclusion, community recreation activities, employment, rights protection, addressing discrimination, postsecondary education, and a wide variety of other key topics. NCD believes that Congress should develop a competitive grant program under AIDD for local self-advocacy organizations, reflecting a similar structure to the Centers for Independent Living program within the Rehabilitation Services Administration, another successful model of federal support to organizations run by people with disabilities.

#### Recommendations

NCD recommends:

- 1.4 The University Centers of Excellence on Developmental Disability, Protection and Advocacy programs, and Developmental Disability Councils, authorized under the Developmental Disabilities Assistance and Bill of Rights Act, should coordinate and expand efforts to support expanded peer support to both families and individuals with intellectual and developmental disabilities moving from sheltered workshop settings to integrated employment.
- 1.5 DD Network partners should be required to coordinate their planning through the establishment of a joint strategic planning process under the Administration on Intellectual and Developmental Disabilities' review. This would enable AIDD to select particular areas of emphasis for systems change activities, which in turn would allow the DD Network partners to pick a particular focus area to coordinate around, such as building state Employment First infrastructure or working to eliminate ICF-MRs<sup>22</sup> within the state.
- 1.6 Congress should establish a relationship between state ID/DD agencies and AIDD, providing AIDD with funding for data collection and systems change grants to state ID/DD agencies and empowering AIDD to require meaningful data collection from state ID/DD agencies, which would better enable AIDD to track progress and promote systems change supporting community integration at the state level.
- 1.7 Congress should establish a competitive grant program for local self-advocacy organizations, similar to the Center for Independent Living model, to be operated through AIDD, which could be a mechanism for both systems change and for encouraging greater social opportunities for people with ID/DD.

# Section 504 of the Rehabilitation Act

# Accessible Currency

On October 3, 2008, United States Court of Appeals for the District of Columbia Circuit Judge James Robertson issued an historic injunction against the United States Treasury Department. In a case brought by the American Council of the Blind and other advocates, Judge Robertson held that the Treasury "violated Section 504 of the Rehabilitation Act by failing to provide meaningful access to United States currency for blind and other visually impaired persons."<sup>23</sup> The Treasury was ordered to take steps to make U.S. currency accessible to people who are blind and/or visually impaired.<sup>24</sup>

Since that time, the U.S. Bureau of Engraving and Printing (BEP) has worked with the Treasury Department and DOJ to increase the accessibility of American paper currency. This process is ongoing, and logistical, technological, and administrative challenges remain to meet the court's mandate and guarantee comprehensive and timely compliance. Questions remain about what the phase-out period should be for the use of existing currency, and how best to determine ways of maximizing accessibility during the transition to new tactile currency.

In December of 2011, BEP reported two key developments:

- In consultation with experts and stakeholders, BEP is researching the most practical method for rendering tactile bills of a denomination larger than \$1.00.
  With periodic reporting to DOJ, BEP anticipates finalization within the near future of the shape and type of tactile symbol to be affixed.
- Interim computer applications (including the Eyenote<sup>™</sup> application for Apple, a free download) and development and distribution of more advanced currency readers will help during the transition period while older inaccessible bills near a

natural obsolescence. Eventually, new paper currency will include symbols and raised textural numbers for bills larger than \$1.00.<sup>25</sup>

#### Recommendations

NCD recommends:

- 1.8 The U.S. Bureau of Engraving and Printing should complete research and set a timetable for commencement of production of tactile currency within two years.
- 1.9 BEP should finalize a plan for how to distribute, or support by voucher application the distribution of easy-to-use handheld currency readers, which will make existing paper currency audibly accessible. Mandatory biannual reports submitted by BEP to the District of Columbia Court and the Department of Justice should be made available to the public, other agencies, and interested parties.

# Housing

In 2006, 2008, and 2010, NCD issued reports<sup>26</sup> focused on housing policy for people with disabilities. In its 2006 and 2008 reports, NCD defined a "livable community" as one that—

- Provides affordable, appropriate, accessible housing;
- Ensures accessible, affordable, reliable, safe transportation;
- Adjusts the physical environment for inclusiveness and accessibility;

- Provides work, volunteer, and education opportunities;
- Ensures access to key health and support services; and
- Encourages participation in civic, cultural, social, and recreational activities.

### Supportive Housing

Supportive housing is a cost-effective, evidence-based approach of combining individualized support services with permanent, affordable rental housing to enable people with disabilities to live successfully in the community, consistent with the Olmstead decision. On January 4, 2011, President Obama signed the Frank Melville Supportive Housing Investment Act of 2010<sup>27</sup> into law.<sup>28</sup> The Frank Melville Act amends the U.S. Department of Housing and Urban Development (HUD) Section 811 Supportive Housing for Persons with Disabilities program by authorizing a cost-effective demonstration program that could triple the number of integrated housing units created through Section 811 without an increase in the program's appropriation, reducing bureaucratic barriers and improving the program's efficiency and cost-effectiveness, and authorizing a cost-neutral shift of fiscal responsibility for the Section 811-funded Mainstream Voucher program to the Housing Choice Voucher appropriation. The law maintains traditional funding of group homes and independent living complexes, while creating a new emphasis on multifamily housing to encourage nonprofit sponsors to set aside up to 25 percent of units in housing developments for Section 811 supportive housing units developed and owned by a nonprofit sponsor.<sup>29</sup> It also creates a new Project Rental Assistance authority to allow HUD to delegate award and oversight of Section 811 operating assistance to the states that can fully fund the initial cost of the units and can show strong collaboration with state health and human service agencies to address the needs of people with disabilities more holistically.<sup>30</sup>

On November 16, 2011, HUD announced \$749 million in housing funds under its Sections 202 and 811 Supportive Housing programs for very low-income people with disabilities and seniors, to assist nonprofits in producing accessible, affordable rental housing and facilitate supportive services. The funding enabled the start of construction or significant restoration of 189 housing developments in 42 states and Puerto Rico that will result in more than 4,800 households with people with disabilities or seniors gaining affordable housing with access to support services.<sup>31</sup>

On March 28, 2012, HUD issued a Notice of Proposed Rulemaking (NPRM) to amend its regulations for Section 202 (Supportive Housing for the Elderly Program) and Section 811 (Supportive Housing for Persons with Disabilities Program) to streamline requirements for mixed-finance developments to attract private capital and expertise to create attractive and affordable supportive housing developments for seniors and people with disabilities.<sup>32</sup> The proposed rules also modernize Section 202 and 811 development regulations by allowing greater flexibility in the design of the units, extending the availability of capital advance funds, and making other technical corrections. The NPRM is the first part of a larger regulatory reform effort of the Section 202 and 811 programs based on the passage of the Frank Melville Act.<sup>33</sup> An additional NPRM is expected out later this year.

#### Housing Discrimination

In the past year, HUD announced several charges of fair housing discrimination on the basis of disability:

 On February 27, 2012, HUD announced that it was charging Bank of America with discrimination against home buyers with disabilities, in violation of the Fair Housing Act, for allegedly requiring borrowers who relied on disability income to qualify for loans to provide statements from their physicians of proof of their disabilities and continuance of their Social Security payments. The charge was announced in concert with work conducted by the Federal Financial Fraud Enforcement Task Force's nondiscrimination working group. The charge was referred to DOJ for additional action.<sup>34</sup>

- On October 24, 2011, HUD announced charges against a Florida-based property owner, management company, and its employees after their refusal to accommodate the request of a resident with a chronic respiratory illness to move to a vacant apartment located between an elevator and a nonsmoking unit after a neighbor's secondhand smoke had twice resulted in the tenant's requiring emergency medical care.<sup>35</sup>
- On October 11, 2011, HUD announced charges against a Utah homeowner association, property management company, and group of condominium owners after refusing to accommodate a Gulf War veteran with a disability who required an emotional support dog. HUD alleges that illegal fees and fines were assessed for the presence of the service animal and that renewal of the tenant's lease was refused until payment was made.<sup>36</sup>
- On October 11, 2011, HUD also announced charges against the University of Nebraska at Kearney and several of its employees following their refusal to permit a therapy dog to live in a university-owned apartment and illegally seeking information from a student with psychiatric disabilities regarding her treatments, prescribed medications, and clinical summary. As a result of the university's refusal, the student had to move out of university housing and withdrew from the college.<sup>37</sup>
- On September 26, 2011, HUD charged the owner and manager of a Washington trailer park with discrimination on the basis of disability for refusing to make reasonable accommodations to a "no pets" policy when testers posing as applicants with disabilities who needed service dogs requested the accommodation.<sup>38</sup>
- On August 24, 2011, HUD announced charges against a housing cooperative in New York as well as two of its employees for their refusal to accommodate an emotional support animal, which had been doctor-prescribed to assist with daily

living for a tenant with disabilities. Following the refusal, the co-op refused to accept the tenant's rent payments and attempted to evict him.<sup>39</sup>

#### Recommendations

NCD recommends:

- 1.10 Similar to the Center for Medicare and Medicaid Services' (CMS) promising practices resources, CMS and the U.S. Department of Housing and Urban Development together should collaborate with states to continually highlight and widely disseminate effective plans, policies, and practices for coordinating housing with community living/long-term care supports across state systems, using a consumer-directed approach.
- 1.11 HUD should improve fair housing enforcement of disability rights, including ensuring that all agencies at the local, state, and federal levels follow HUD's guidance to "affirmative further fair housing" for people with disabilities by reviewing and eliminating obstacles to accessible housing.
- 1.12 HUD should expand accessibility features within registries, such as features for people with sensory (vision, hearing, tactile), developmental, and psychiatric disabilities; autism; and environmental sensitivities.
- 1.13 Congress should fund mechanisms for community-based organizations, such as Centers for Independent Living, Area Agencies on Aging, and Aging and Disability Resource Centers, to coordinate and maintain housing information along with community living support and program information, so consumers can have real choices and make informed decisions.

- 1.14 HUD should work in collaboration with the Department of Justice, the Administration on Intellectual and Developmental Disabilities, the new Administration on Community Living and other relevant stakeholders in both government and the advocacy community to restructure its programs to reflect consistency with the Supreme Court's *Olmstead v*. *L.C.* decision and the integration mandate of the Americans with Disabilities Act.
- 1.15 HUD should step up its efforts to enforce the Fair Housing Act rights of people with disabilities attending colleges and universities, including people with intellectual disabilities in nondegree-granting programs.

#### Home- and Community-Based Services and Supports

#### CMS Works to Define Community Living

Over the history of Medicaid Home- and Community-Based Services (HCBS), the Federal Government has worked consistently to incentivize the expansion of HCBS as an alternative to institutions and nursing homes for people with disabilities. A wide array of efforts have been undertaken to increase the percentage of Medicaid Long-Term Services and Supports (LTSS) dollars going to community-based service provision and to decrease the percentage allocated to institutional care, including the Money Follows the Person (MFP) program; federal litigation to promote state compliance with the *Olmstead* decision; and substantial advocacy efforts on the part of local, state, and national disability rights organizations. In response to these efforts, many states have shifted their Medicaid spending toward HCBS and diminished their spending on institutional care.

Unfortunately, in response to this shift, certain questions have emerged as to how to appropriately define what is and what is not HCBS service provision. Certain states and

providers have attempted to use HCBS funds for services outside the intent or purpose of the HCBS program, such as gated communities, disability-segregated farmsteads, or clustered group homes and settings on the grounds of or immediately adjacent to an institution or nursing home.

In April 2011, the CMS aimed to address this problem through an NPRM proposing a three-pronged definition of what could and could not be considered a community-based setting under Medicaid.<sup>40</sup> The NPRM set out the following standard: "…HCBS settings: must be integrated in the community; must not be located in a building that is also a publicly or privately operated facility that provides institutional treatment or custodial care; must not be located in a building on the grounds of, or immediately adjacent to, a public institution; or, must not be a housing complex designed expressly around an individual's diagnosis or disability, as determined by the Secretary. In addition, we propose that the settings must not have qualities of an institution, as determined by the Secretary. Such qualities may include regimented meal and sleep times, limitations on visitors, lack of privacy and other attributes that limit individual's ability to engage freely in the community."

This proposed definition received substantial feedback, both positive and negative, during the public comment process. As a result, CMS did not issue a final rule defining HCBS for the 1915(c) waiver, as it had proposed to do. Instead, the agency chose to revise its proposed definition of "community" (and solicit additional public comment) within the regulations promulgating the 1915(i) Medicaid state plan option, as established by the Patient Protection and Affordable Care Act (ACA). In so doing, the agency indicated its intention to standardize the definition of community across 1915(i), 1915(k), and 1915(c) to ensure a uniform definition of community across every HCBS funding authority within the Medicaid program. The revised definition of HCBS carried some positive innovations, such as a requirement that states develop a quality assurance system utilizing individual outcome measures to monitor provider compliance with setting requirements and person-centered planning. However, there are also elements of significant concern in CMS' new proposed definition, such as an allowance

for exceptions to the setting and characteristic requirements of HCBS settings on an individual basis. While a flexibility-based approach may carry benefits, concerns exist as to the greater possibility of abuse under this model.

# **Community First Choice Option**

On April 26, 2012, HHS finalized the rule implementing the Community First Choice (CFC) Option of the ACA.<sup>42</sup> The CFC Option is a new state plan option under Medicaid that will allow people to receive health services and support in their communities more easily rather than in hospitals or institutional settings. The former have been shown to be more cost-effective and increase the independence and improve the quality of life of those in need of such services. Absent "setting" requirements, final regulations effective July 6, 2012, define eligibility, specify services that must be made available under the CFC Option, call for a self-directed model of service provision, and confirm that states that opt for the CFC state plan option will receive an additional 6 percent in Federal Medical Assistance Percentage for the provision of those services and supports.<sup>43</sup>

On February 22, 2011, HHS announced \$4.3 billion in new funds to help establish and expand community-based alternatives to institutional long-term care through increased funding for the MFP demonstration program and the CFC Option programs. Thirteen new states plus 29 already approved states will together receive more than \$45 million in MFP grants under provisions of the ACA to start programs in their states, with a total of \$621 million committed through 2016. In addition, HHS proposed rules to allow all states to access a total of \$3.7 billion in increased federal funding to provide long-term services and supports through the CFC Option program.<sup>44</sup>

#### Recommendations

NCD recommends:

- 1.16 The Center for Medicare & Medicaid Services should further refine its definition of Home- and Community-Based Service provision in consultation with the disability community to differentiate HCBS more clearly from congregate care models, utilizing a definition that excludes gated communities, segregated farmsteads, clusters of group homes, settings that restrict personal choice and control, and other settings with the characteristics of an institution. CMS may wish to consider developing distinct definitions of HCBS for senior citizens and nonseniors with disabilities.
- 1.17 Congress should explore various mechanisms to further enhance the Federal Medicaid Assistance Percentage (FMAP) available to Home and Community Based Services and to reduce the FMAP for Institutional Services.
- 1.18 Eligible states should adopt and implement the various mechanisms within the Affordable Care Act supporting the expansion of HCBS, including the Community First Choice State Option, the State Balancing Incentive Program and the reauthorized Money Follows the Person Demonstration Grants.

#### **Healthy Living**

#### Health Care Disparities

When NCD released its 2009 health care status report on people with disabilities,<sup>45</sup> defining disability as a demographic characteristic was still a fairly radical concept, given that disability—particularly within the health care field—has traditionally been considered a medical diagnosis, rather than a demographic identifier. Through extensive community engagement and review of available national disability data, NCD found that vast disparities exist between people with and without disabilities in access to health care. The overall findings have seen little change since NCD's 2009 report.

People with disabilities tend to be in poorer health and to use health care at a significantly higher rate than people who do not have disabilities. They also experience a higher prevalence of secondary conditions and use preventive services at lower rates. People with disabilities experience more problems accessing health care than other groups, and these difficulties increase for people with the most significant disabilities and who are in the poorest health. The lack of access to health care has been associated with increased risk for secondary conditions for people with significant disabilities.<sup>46</sup> Despite these persistent and long-standing problems, people with disabilities are still not included within the federal government's definition of "medically underserved population."

Since the passage of the ACA in 2010, HHS and other federal agencies and groups have shown support for the view that disability is a demographic identifier and have begun to address unique health disparities among people with disabilities. For example, the 2011 Health Brain Trust, an annual conference sponsored by the Congressional Black Caucus, included disability as a diversity factor in its sessions about racial, ethnic, and gender health disparities.<sup>47</sup> During that conference, HHS introduced newly formed teams of internal division and office leaders responsible for addressing health disparities, including those of people with disabilities. NCD has taken note of these

efforts and is heartened by these developments. Replication and further development of these and similar federal efforts are critical in addressing health care disparities, particularly with regard to the inclusion of people with disabilities in health care data collection and disaggregation used to inform public policy making.

#### Insuring People with Preexisting Conditions

A number of the provisions of ACA give people with disabilities great hope for improved access to health care and health insurance. One ACA provision most heralded within the disability community has been the prohibition of coverage or eligibility denial on the basis of preexisting medical conditions or health status. This provision went into effect September 23, 2010, for children and goes into effect on January 1, 2014, for adults. In a congressional memorandum released shortly after the passage of ACA, a House Energy and Commerce Committee investigation found that the four largest for-profit health insurance coverage due to preexisting conditions during the three years directly preceding the ACA's passage and that the number of denials had increased significantly each of those years, despite a far more modest increase in enrollment applications.<sup>48</sup>

Following passage of the ACA in 2010, 26 states brought a multi-state lawsuit against the Federal Government, challenging the constitutionality of the requirement that those who do not have health insurance must purchase it or incur a fine; and the law's expansion of the Medicaid program, which was taken up by the Supreme Court. Several disability and aging groups filed an amicus brief with the Supreme Court in support of the ACA and specifically the ban on the denial of coverage for preexisting conditions.<sup>49</sup> In one brief, amici warn that without the ability to obtain insurance, individuals with disabilities are at serious financial and medical risk, and that barriers to access to health insurance cause postponements in timely diagnosis and treatment until both are more expensive and less effective.<sup>50</sup> On June 28, 2012, in a 5-4 decision, the U.S. Supreme Court upheld ACA. In its ruling, the Supreme Court found that the requirement that

individuals must have health insurance or pay a fine was constitutional under Congress's taxing authority. While also finding constitutional the expansion of the Medicaid program, the Court limited the enforcement of those provisions by ruling that the Federal Government may not remove existing funding from states that do not Medicaid expand eligibility. As a result, some states may elect to not expand Medicaid, although federal funding incentives still exist to do so.

### **Disability Research<sup>51</sup>**

A growing body of evidence shows the need for patient-centered research in efforts to assess the relationship between particular interventions, treatments, and other forms of health care and the quality of life of those receiving them. In addition to questions of quality, efforts by the Federal Government, health professionals, and others to address, reduce, and/or contain public health costs must ensure that people with disabilities are included in planning and implementation.

To accomplish this, federal research funders should serve as a model for private funders by highlighting various mechanisms to involve people with disabilities throughout the research process. Involving people with disabilities in the grant review process constitutes a significant opportunity to enhance the disability community's role in assessing which scientifically valid research priorities have the greatest impact on the lived experiences of people with disabilities and their family members. Furthermore, the use of Community-Based Participatory Research/Participatory Action Research models—where the population being studied is involved as a full partner at each stage of the research process—poses significant opportunities for ensuring greater community relevance and reliability of research findings.

Historically, NCD has called for research that disaggregates data and compares information on people with disabilities with information on their peers without disabilities. Similar principles can be applied to traditional vs. nontraditional treatment options. A positive step forward in the health care arena is that the U.S. Food and Drug Administration and the Institute of Medicine at HHS highlight the importance of valid and

reliable measurement of patient-reported outcomes in the evaluation of conventional and alternative medical products.<sup>52</sup> Similar efforts to measure effectiveness and quality of various health care treatments should be undertaken in consultation and collaboration with the disability community.

#### Medicaid Managed Care

This year, NCD undertook efforts to respond to the growing shift away from fee-forservice and toward managed care payment mechanisms within the Medicaid program. NCD's efforts focused on articulating implications of managed care arrangements in publicly financed service systems for people with disabilities and on providing guiding principles for enrolling people with disabilities in managed care plans.

Managed care has historically been used primarily in the context of acute care services for adults without disabilities. The economic recession and new demonstration authority within the ACA for integrating services for the dual-eligible population has led more states to move to adopt managed care models for people with disabilities, in the context of both LTSS and acute care. A number of states have successfully used managed care models for their Medicaid systems, including LTSS. However, additional capacity must be built to ensure that the needs of people with disabilities are met in managed care frameworks.

For example, the issue of quality measurement—critical to successful managed care contracts—requires elaboration to ensure that indicators adopted to assess health care quality do not overly medicalize LTSS for people with disabilities. The National Quality Forum is the nonprofit entity with lead responsibility for determining the measures that should be recognized as national standards. Among the more than 1,500 measures approved to date, only a handful are connected to LTSS as opposed to traditional acute care—and those primarily relate to behavioral health and early childhood development.<sup>53</sup> NCD believes that CMS must undertake efforts to ensure that states shifting to managed care models adopt safeguards to ensure that people with disabilities are not adversely affected.

#### Recommendations

NCD recommends:

- 1.19 The U.S. Department of Health and Human Services should ensure the inclusion of people with disabilities within the definition of "medically underserved populations," as well as within other relevant categories relating to the acknowledgment of disparities in access to health care and equal access to research funding and related benefits aimed at decreasing health disparities.
- 1.20 Prior to approving a state application to implement a managed care program, the Center for Medicare & Medicaid Services must conduct a state readiness assessment to determine whether the submitting state has in place the resources and capacity necessary to effectively administer and oversee the proposed managed care program, and to hold managed care entities accountable for their performance. The readiness assessment must include a review of the state's plan and operational capacity, as well as the requirements set out in the contracts between the state and the managed care entities.
- 1.21 CMS should require states to commission an independent evaluation of their managed care programs and make the submission of the findings and conclusions growing out of this evaluation a condition of a state's renewal request.
- 1.22 While federal statutes and regulations have established expectations for ongoing quality assessment and performance improvement programs in managed care settings, the tools most commonly used for monitoring quality in Medicaid managed care are primarily focused on acute care and

are not relevant to the provision of long-term services and supports for people with disabilities. CMS must establish a process for ensuring that measurement tools that are normed on the various sub-populations enrolled in managed care programs encompassing LTSS can be employed by states to monitor performance. For example, for the intellectual/developmental disability population, National Core Indicators is a nationally recognized tool for monitoring quality of LTSS. Performance indicators should address key domains such as individual outcomes (employment, access to and participation in community life, contact with friends and family), participant rights, and family outcomes. CMS must ensure that an accessible, disability-competent quality assessment and performance improvement process is applied to both Medicaid-only managed care arrangements and managed care arrangements relating to the dual-eligible demonstration projects authorized under the Affordable Care Act. HHS should ensure that its research funding agenda does not curtail or exclude investigations that gather data on the impact of nontraditional treatment measured against traditional treatments. Choices among various evidence-based treatments must remain available for all people with physical and/or mental health care needs.

1.23 HHS, placing particular emphasis on the National Institutes of Health, Agency for Healthcare Research and Quality, and Health Resources and Services Administration, should work to ensure that its disability research agenda is aligned with the priorities of the disability community and meaningfully includes people with disabilities and the organized disability community at every step, from priority setting and grant review to study design, data collection, and interpretation of findings. The use of Community-Based Participatory Research/Participatory Action Research models and the inclusion of people with disabilities in the grant review process should both be prioritized toward these ends.

#### **Military Health Care**

Active service members, their family members with and without disabilities, returning veterans, and veterans of former wars all need reliable and effective health care. Difficulties with navigating systems, obtaining timely referrals, and encountering shortages of providers, particularly in the area of mental health, can dramatically affect those in need of services and supports.

#### Active Duty Care for Exceptional Family Members (EFM)

For its 2011 report, *United States Marine Corps Exceptional Family Members: How to Improve Access to Health Care, Special Education, and Long-Term Supports and Services for Family Members with Disabilities,* NCD collected stories of the experiences of the United States Marine Corps community through focus groups and interviews with caretakers, family members with disabilities, and service providers at three large bases where many EFM families are assigned: Marine Corps Base Quantico, Camp Lejeune, and Camp Pendleton.<sup>54</sup> Active service members, their families, and service providers told NCD of numerous barriers to meeting health care needs.

Specifically, EFM participants reported encountering (1) inconsistent processes across military locations for obtaining information about health services, (2) a lack of quality health care specialists, and (3) difficulty obtaining timely referrals and appointments near military installations. Family members with disabilities often go untreated when they are denied access to or are unaware of available help. EFM children often face shortages of pediatric and mental health specialists.<sup>55</sup>

#### Veterans' Mental Health Needs

"The statistics are sobering—18 veterans commit suicide each day with almost a third receiving care from the Department of Veterans Affairs (VA) at the time of their death.... Each month, there are 950 veterans being treated by VA who attempt suicide. What's more, data from the U.S. Department of Defense indicate service members took their lives at an approximate rate of one every 36 hours from 2005 to 2010."

> —Chairwoman Ann Marie Buerkle, Veterans Committee, Subcommittee on Health, U.S. House of Representatives<sup>56</sup>

Five years have passed since the U.S. Department of Defense (DoD) sent a Mental Health Task Force Report to Congress in 2007. The task force based its work on the vision of transforming military mental health care through four goals: creating a culture of support for psychological health; a full continuum of excellent care; sufficient and appropriate resources; and visible and empowered leaders.<sup>57</sup> In announcing its subsequent corrective action plan, DoD stated, "The department is working to provide a comprehensive integrated system of excellence in prevention and care, to meet the needs of individual service members and their families throughout the military lifecycle. We have a strong partnership with the U.S. Department of Veterans Affairs (VA) and the Department of Health and Human Services (HHS) to build a safety net of care for our military families.<sup>58</sup> However, despite plans and efforts, the accounts of unmet mental health needs and often devastating outcomes for veterans with disabilities continue.

While waiting for systems change, litigation can be a viable path by which a number of veterans receive the mental health service benefits they require. For example, while fulfilling his U.S. Army role in Iraq, a single father of two was in multiple firefights, and his vehicle was struck by improvised explosive devices. He was told that he could no longer serve in the military owing to his post-traumatic stress disorder (PTSD) and was separated from the military with a low disability rating that denied him TRICARE benefits. In an historic class action settlement announced in July 2011, he and his children were restored their veterans' health benefits.<sup>59</sup>

Congress has also focused much attention on the mental health care of thousands of U.S. veterans and their families through a variety of hearings over the past year.<sup>60</sup> These hearings, held in the Senate, in the House, and jointly, have highlighted several key problems that continue to plague the system, including long wait times for critical

services and significant mental health staffing shortages.<sup>61</sup> University researchers reported three years ago that a many veterans with service-connected disabilities live in rural communities;<sup>62</sup> veterans in underserved areas need professionals and facilities for physical and mental health care. The Rural Assistance Center reports that the primary barrier facing this rural veterans' population is the geographic distance from the nearest VA health facility.<sup>63</sup> In some areas, vacancies for mental health care practitioners serving veterans have been as high as 23 percent.<sup>64</sup>

In April 2012, the VA announced that roughly 1,600 mental health clinicians—nurses, psychiatrists, psychologists, and social workers, as well as nearly 300 support staff--would be added to the VA's existing mental health workforce.<sup>65</sup> NCD acknowledges reports of VA actions to begin this hiring, with completion targeted for the end of 2012, and a promise to continue assessing staff needs.<sup>66</sup> Also in April 2012,, the VA announced it had also expanded its mental health services to include marriage and family therapists as well as licensed professional mental health counselors.<sup>67</sup> That same month, Joining Forces,<sup>68</sup> in coordination with the VA and DoD, announced a commitment from 150 nursing organizations and 500 nursing schools to further educate more than 3 million nurses on the unique health care needs of service members, veterans, and their families, with a specific focus on PTSD, traumatic brain injury, depression, and other combat-related concerns.<sup>69</sup>

#### Life Transition Challenges

Some service members transitioning to civilian status develop health care needs that affect daily living for them as well as their families, particularly when unmet physical and mental health needs surface. In March 2012, the House Veterans' Affairs Committee's Subcommittee on Disability Assistance and Memorial Affairs held a hearing to examine the implementation of the new Integrated Disability Evaluation System (IDES) by DoD and the VA. IDES was designed to aid wounded warriors and their families in the transition from active duty to veteran status when, as a result of physical or mental injuries, a service member's duty status is at issue. Testimony at the hearing outlined

ongoing problems with lengthy delays and difficulty navigating the system. IDES pilot programs significantly decreased the 500-day process time of the system it was designed to replace, but once IDES expanded to more locations, its process time lengthened to 500 days as well.<sup>70</sup>

#### Recommendations

- 1.24 The Department of Defense and the Veterans Administration should develop and carry out a plan to ensure continuous availability of physical and mental health services for all active service members and veterans. The plan must ensure that people with post-traumatic stress disorder and traumatic brain injury, which may manifest after leaving the military, have ongoing access to mental health services both before and after their military separation.
- 1.25 DoD and the VA should identify and build upon lessons learned from the model of training veterans to become vocational rehabilitation counselors, and determine effective ways to apply the principles to combat the staff shortages in mental health professionals.
- 1.26 Tricare should increase the accuracy and timeliness of information accuracy and timeliness of information Exceptional Family Members families receive from TRICARE by instructing case managers to assist families in accessing services, assigning TRICARE case managers to a larger proportion of the EFM population, and establishing multiple communication mechanisms, including a dedicated TRICARE telephone hotline (staffed 24/7) for EFM families, similar to the Medicare hotline.

#### **Emergency Management**

In 2011, NCD participated in two events that focused on the importance of effective communication with people with disabilities before, during, and after an emergency. First, NCD collaborated with the Federal Emergency Management Agency (FEMA) Office of Disability Integration and Coordination on an inclusive emergency preparedness conference titled "Getting Real II," in September 2011. This conference highlighted promising practices in inclusive emergency management. To increase participation in the conference and dissemination of the information, the conference was webcast via a live stream online.<sup>71</sup> In addition to the conference's 400 attendees (who came from 37 states and Guam), 2,826 people viewed the webcast, with 80 percent coming via direct traffic and 10 percent international traffic, primarily from Japan, Canada, Germany, and the United Kingdom, as well as Africa.

Also in September 2011, NCD held an all-day meeting with FEMA's Regional Disability Integration Specialists (RDISs), at which the agencies discussed the current state of emergency management as well as access for people with disabilities. Later, in February 2012, NCD and FEMA's RDISs held a follow-up conference call to discuss NCD's anticipated effective communication report as well as potential for further collaboration between the agencies.

The lack of enforcement of federal laws affecting people with disabilities is a significant problem reflected in legal complaints filed. Although DOJ has not reported comparison data, readers can access settlement agreements resolving complaint-based investigations and compliance reviews online.<sup>72</sup> For example, advocates filed a class action complaint against New York City for inaccessible evacuation maps, lack of plain language to clarify messages across levels of understanding, failure to provide sign language interpreters, and other allegations.<sup>73</sup>

In addition to the aforementioned events, NCD obtained feedback from stakeholders regarding the nationwide November 2011 Emergency Broadcast System test.<sup>74</sup>

At the writing of this progress report, NCD was beginning a comprehensive report intended to provide cross-disability perspectives and recommendations for communication improvements within emergency management practices. NCD proposes to collect information on the experiences of people with disabilities as they relate to emergency-related communication; highlight best and promising practices; and determine recommendations for how emergency communication accessibility for people with disabilities can be improved. NCD is also looking at current disability laws and regulations as they pertain to effective communication before, during, and after emergencies; the enforcement of these laws and regulations; and whether further laws and/or regulations should be pursued. NCD hopes the information in the report will motivate and drive emergency planners to improve their ability to provide effective communication for people with disabilities,<sup>75</sup> and their parents who also are living with their own disabilities. NCD anticipates concluding work on this project some time in 2013.

#### Recommendations

NCD recommends:

1.27 The U.S. Department of Justice, in collaboration with the Federal Communications Commission as appropriate, must increase the enforcement of disability laws and regulations as they pertain to effective communication before, during, and after emergencies for people with disabilities. Specifically, state and local emergency management officials must comply with their effective communication legal obligations. In addition, television broadcasters must adhere to laws and regulations regarding the accessibility of emergency information.

# **Parenting Rights**

There are approximately nine million parents with disabilities in the United States, and that number is expected to grow in this century.<sup>76</sup> Currently, many states' child custody laws permit a parent's disability to be an acceptable reason to deny custody or visitation, even in instances in which a parent with a disability has successfully parented for years prior to an ended relationship or divorce. After repeatedly hearing of these concerns from NCD stakeholders and receiving a thorough briefing of the topic at NCD's regional "Living Forum" in Portland, Oregon, in May 2011, NCD embarked on a policy project regarding parenting rights of people with disabilities, which will culminate in a report later this year titled *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children*.<sup>77</sup>

In undertaking this research project, NCD identified several areas on which to focus its research and policy recommendations:

- Overcoming discriminatory presumptions—societal attitudes as well as policies, practices, and procedures—that people with disabilities are "unfit" to be parents;
- Removing barriers to creating families for people with disabilities (reproductive health care access, including access to adoption and assisted reproductive technologies);
- Educating health professionals and the general public about challenges to parents with disabilities and enforcement of Titles II and III of the ADA;
- Making available parenting guidance about children with disabilities similar to data made available on other special populations;
- Ensuring that child welfare systems will recognize and assume their legal duty to appropriately serve parents with disabilities and their families; and
- Providing funding for supports needed to serve parents with disabilities.

People with disabilities continue to experience significant barriers to creating a family that their peers without disabilities do not encounter. For example, child welfare agencies often do not provide parents with disabilities appropriate accommodations to support child rearing. Family courts also make a priori assumptions about people with disabilities being unable to raise children simply because of their various disabilities. These assumptions often result in denial of child custody and other related rights.<sup>78</sup>

In addition, federal agencies omit letters of findings and fact sheets on Web sites that can serve as adoption guidance for parents with disabilities. For example, the Office for Civil Rights at HHS provides letters of findings and agreements with state entities on the legal protections for prospective parents of diverse races, colors, and national origins seeking to adopt.<sup>79</sup> However, it does not give similar guidance concerning the rights of prospective parents with disabilities.

NCD's anticipated 2012 publication, *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities,* will seek to improve understanding and promote the rights of parents with disabilities and their children. *Rocking the Cradle* will provide a comprehensive review of the barriers and supports people with disabilities experience when exercising their fundamental right to create and maintain families. The report will highlight the systemic and pervasive discrimination against parents with disabilities. It will provide an analysis of how federal disability law and policy applies to parents with disabilities within the child welfare system and the family law system and the systems' disparate treatment of parents with disabilities and their children. The report will also review the impediments prospective parents with disabilities encounter when adopting, both domestically and internationally, and when attempting to access reproductive technologies.

#### Recommendations

NCD recommends:

- 1.28 The U.S. Department of Justice should issue guidance to family courts on their legal obligations pursuant to the Americans with Disabilities Act. Such guidance must address (1) the applicability of the ADA to custody and visitation proceedings, (2) the courts' duty to provide reasonable accommodations to parents with disabilities, and (3) per se presumptions of parental incompetence based on disability that violate the ADA.
- 1.29 The U.S. Department of Health and Human Services and DOJ should gather annual data on parents with disabilities and their interaction with child welfare and dependency court systems. Such data must include (1) disability, (2) exact involvement, (3) services and reasonable accommodations provided, and (4) outcome.

# Transportation

"It is hereby declared to be the national policy that elderly and handicapped persons have the same right as other persons to utilize mass transportation facilities and services; that special efforts shall be made in the planning and design of mass transportation facilities and services so that the availability to elderly and handicapped persons of mass transportation which they can effectively utilize will be assured; and that all Federal programs offering assistance in the field of mass' transportation (including the programs under this Act) should contain provisions implementing this policy."

—Urban Mass Transportation Act of 1970)<sup>80</sup>

Billy Altom, executive director of the Association of Programs for Rural Independent Living, cited the statutory language from the Urban Mass Transportation Act of 1970 when he testified at a Senate hearing on challenges and opportunities to accessible transportation for people with disabilities. He said, "The above 1970 statutory language, establishing national transportation policy, was written 20 years before the 1990 Americans with Disabilities Act (ADA). We need to use the 1970 Transportation Act's words as a challenge and a reminder of promises to keep."<sup>81</sup>

Indeed, transportation continues to be one of the most critical challenges for Americans with disabilities. Whether to school, to the office, the gym, or the grocery store, "getting there" is the necessary first step to participating in activities that positively influence one's quality of life. Still, for millions of Americans with disabilities, the question "How will I get there?" remains unanswered. There is no doubt that transportation is one of the most critical and cherished elements of modern independent living. Urgent attention and progressive campaigns to increase integrated access are critical.

#### Ground Transportation

Ground transportation is essential for everyone to access jobs, recreation, shopping, friends, and family. Consistently positive, accessible transportation experiences are often indicative of coordination and collaboration among passengers, public and private transportation providers, human service agencies, and a variety of funding sources. However, too often, these elements are not coordinated, and resulting barriers to access confound people's efforts to find and maintain employment, social integration, and full participation.

People with disabilities who move to cities may do so in part to take advantage of public transit; those who live in suburban, rural, or remote areas without access to public transportation options may face isolation. However, even for people with disabilities who live in urban centers, subways, buses, paratransit, taxis, and limousine services often require many improvements to be fully accessible.

Subway construction and renovations are not routinely carried out with accessibility in mind. The results are new or renovated stations that fail to include necessary elevator access or do not extend access to the platform.<sup>82</sup> Repeatedly, elevators in existing subways are closed for safety or mechanical reasons. Gaps between platforms and the trains may prevent passengers using wheelchairs from entering trains even if they make it to the platform level.

Paratransit systems continue to be riddled with problems, including overall scarcity, monumental delays, fare increases, driver failure to assist when needed, and service eliminations due to budget cuts. The net result of many of these problems is at best significant delays for some passengers whose busy schedules are regularly compromised; and at worst, being left completely stranded and isolated due to eliminated service.

Private urban transportation systems, including taxis and limousines, are equally unworkable and continue to operate without cross-coordination. People with disabilities who use service animals are routinely denied access altogether. While London taxis are 100 percent accessible, the New York City (NYC) fleet of more than 13,000 taxis has fewer than 250 accessible cabs; and but for litigation, NYC's proposed "green" taxi fleet would reduce that number to zero.<sup>83</sup>

In September 2011, the U.S. Department of Transportation (DOT) issued a final rule on transportation for people with disabilities at intercity, commuter, and high-speed passenger rail station platforms, which became effective a month later.<sup>84</sup> The rule requires that full-length, level-entry boarding be available at new or altered commuter, intercity, and high-speed station platforms where no tracks are shared with freight.<sup>85</sup> However, where a station is shared with freight, the performance standards are more flexible. If the station cannot provide full-length level-entry boarding, the rule permits car-borne lifts, station-based lifts, or mini-high platforms once its plan for meeting the performance standard is approved by the Federal Transit Administration or Federal Rail Administration.<sup>86</sup> The rule also removes the definition of a "common wheelchair" from the regulation, as the original concept had come to be applied to exclude certain

wheelchairs even if train cars and equipment could accommodate them.<sup>87</sup> Although the disability community was overall quite pleased with the positive developments in the final rule, many have voiced frustrations with the freight industry's rejection of level-boarding platforms, and with questions regarding DOJ's level of jurisdiction in enforcing the new provisions.

# Public Rights-of-Way

On the 21<sup>st</sup> anniversary of the ADA, the Architectural and Transportation Barriers Compliance Board issued proposed guidelines for accessible public rights-of-way and held two hearings on the guidelines in October and December 2011, during the open comment period.<sup>88</sup> The proposed guidelines address sidewalks, pedestrian signals and crosswalks, and other pedestrian facilities so that their design, construction, or alteration ensures that they are readily accessible to and usable by people with disabilities. The comment period for the proposed guidelines closed in February 2012.

#### Air Travel

Intercity and international travel pose equal difficulties for passengers with disabilities. The Air Carrier Access Act (ACAA) prohibits discrimination by domestic and foreign airlines against passengers with disabilities and applies across the entire flying experience, from reservations, boarding, and deplaning to the way mobility devices are handled.<sup>89</sup> However, a lack of personnel training has contributed to ongoing discriminatory experiences. In fact, the number of complaints filed with the Aviation Consumer Protection (DOT) alleging discrimination against people with disabilities who are using airlines has increased in the past two years.<sup>90</sup> Security checkpoints are often at a loss for how to deal with passengers with disabilities.

In November 2011, NCD Chairman Jonathan Young presented at an ACAA 25<sup>th</sup> anniversary event, held in collaboration with DOT and the Airline Transport Association. Young cited evidence of progress shown through recent DOT initiatives that address

issues of access for people with disabilities in U.S. airports to tickets, kiosks, and foreign travel.<sup>91</sup> However, while acknowledging progress, Young told participants that people with disabilities continued to be at the mercy and discretion of airlines, and that more improvements were needed.

Despite progress made by DOT to address areas needing improvement, people with disabilities continue to report frustrations with basic accommodations, access, staff training, broken equipment, unequal treatment, disrespect, and overall negative attitudes displayed by many airport employees.<sup>92</sup> In addition, as seen in three DOT fines imposed on airlines to date, many of these disability-based complaints are not properly reported.<sup>93</sup>

In 2011, NCD met with representatives of the Transportation Security Administration (TSA) to discuss concerns of air travelers with disabilities regarding security screenings.<sup>94</sup> As a result, TSA formed an Integrated Product Team to conduct an extensive review of the sections of the Screening Checkpoint Standard Operating Procedures that apply to people with disabilities and medical conditions. Additionally, the team is collaborating with TSA's Office of Technical Training on a complete redesign of the training curriculum for serving passengers with disabilities. NCD applauds TSA for launching the TSA Cares hotline for airline passengers with disabilities and special medical needs. Passengers can also now request a TSA official to answer airport screening questions.<sup>95</sup>

#### **Other Transportation Accessibility Challenges**

The final transportation frontier for people with disabilities lies in America's suburbs, rural, and remote areas. People with disabilities who are forgotten time and again include Alaska Natives and some members of tribal communities on pueblos, rancherias, and reservations in need of viable road systems, as ground transportation, and air travel.

More than a decade has passed since a key NCD report emphasized that inaccessibility of transportation is not limited to vehicular barriers. Examples include inaccessibility of

print-only maps, timetables, signage, announced-only delay or detour information, and fare and ticket machines.<sup>96</sup> The breadth of problems related to transportation and the degree to which they affect the quality of life for Americans with disabilities will require strong inquiry and modification.

#### Recommendations

NCD recommends:

- 1.30 Congress should conduct a hearing to examine the experiences of air travelers with disabilities, industry best practices, and enforcement activities by the U.S. Department of Transportation; and develop corrective actions to make nondiscrimination in air travel a reality.
- 1.31 The Transportation Security Administration should enforce compliance with its security screening policies and procedures to ensure the accessibility of aviation security screenings for all people with disabilities, including wheelchair users and people with invisible disabilities.

# United Nations Convention on the Rights of Persons with Disabilities (CRPD)

The CRPD was adopted as a response to the reality that while existing human rights conventions offer considerable potential to protect the rights of people with disabilities, this potential was not being realized. Around the globe, people with disabilities are still denied basic human rights and kept on the margins of society.

The CRPD sets out legal obligations to promote and protect the rights of people with disabilities. It was created, in part, to address an overlooked development challenge. Approximately 10 percent of the world's population is people with disabilities (more than

650 million people), approximately 80 percent of whom live in developing countries.<sup>97</sup> The CRPD seeks to shift the focus away from the perception of people with disabilities as "objects" of charity, medical treatment, and social protection toward recognizing them as "subjects" with rights, who are capable of claiming those rights and making decisions about their lives with informed consent as engaged, valuable, and active members of society.<sup>98</sup>

As of April 2012, there have been 110 ratifications and 153 signatories to the CRPD. To date, there have also been 63 ratifications of the Optional Protocol, including 90 signatories. The international disability community is embracing the new legal framework in the CRPD. NCD continues to recommend that when the Senate receives the ratification package, it expeditiously consents to ratify the CRPD. The CRPD provides the United States with a tool to promote nondiscrimination and equality for people with disabilities worldwide.

In addition, the current Disability Policy of the U.S. Agency for International Development (USAID), drafted in 1997, is outdated and provides minimal guidance on how USAID programs can be made inclusive across all sectors of its development portfolio. A review and revision of the 1997 policy should also redouble efforts to ensure inclusion in all programming and provide specific, concrete, and achievable guidance to USAID personnel and implementing partners. An emphasis on training that reaches USAID personnel in Washington, as well as in missions around the world, is clearly needed. The development of disability indicators to enrich the monitoring and evaluation of USAID's programs is likewise timely.

In June 2010, the Obama Administration created a new position, the Special Advisor on International Disability Rights, within the U.S. State Department (DOS) to further its commitment to supporting the CRPD. The purpose of the Special Advisor is to "include issues affecting people with disabilities across the world in all aspects of [DOS] work."<sup>99</sup> NCD commends this appointment and recommends that DOS provide adequate resources to achieve the objectives of that office, such as providing proper staffing and finances for the office and promoting agency-wide coordination.

#### Recommendations

- 1.32 The United States should expeditiously ratify the UN Convention on the Rights of Persons with Disabilities.
- 1.33 The U.S. Agency for International Development should review and update its Disability Policy.
- 1.34 USAID should provide adequate resources for the Coordinator on Disability and Inclusive Development. NCD recommends that USAID provide ample resources for the Coordinator on Disability and Inclusive Development to advance implementation of the USAID Disability Policy. USAID should provide proper staffing and finances for this work and should promote agency-wide coordination. Additionally, USAID should promote interagency coordination between this office and DOS to promote disability inclusion in all international diplomacy and development work.
- 1.35 Congress should instruct USAID, the Department of State, the Department of Defense, as well as other U.S. agencies operating overseas to promote greater comparative knowledge and understanding of local disability law and policy frameworks, including the status of CRPD ratification in countries receiving foreign assistance.
- 1.36 DOS should provide adequate resources for the Office of the Special Advisor on International Disability Rights to promote disability inclusion in all aspects of DOS work.

# CHAPTER 2. Learning

# Introduction

Students with disabilities in the 21st century face persistent barriers to a free appropriate public education, despite the protections in the Individuals with Disabilities Education Act (IDEA) and Section 504 of the Rehabilitation Act of 1973. Schools in which students with and without disabilities learn side by side are essential to quality educational outcomes for all students. Disability-specific or segregated charter schools for students with disabilities are contrary to the social, civic, and educational advances embraced by IDEA and other seminal education reforms. Education must move forward, and not return to the failed segregation practices of decades past.

#### NCD's Experts Symposium and Town Hall on Education Reform

In March 2012, NCD hosted an Experts Symposium titled "Raising Expectations: A Disability Framework for Education Reform," in Orlando, Florida. The symposium brought together approximately 30 experts from general and special education to discuss the effect of a variety of education reforms on students with disabilities and assist NCD in the development of a policy toolkit that state departments of education, legislatures, and local school districts can use to help evaluate education reforms for students with disabilities. Each expert participant was a part of a working group that delved into specific aspects of education reform. Working groups included "Common Core and Access to the General Curriculum," "Vouchers and Charter Schools," and "Graduation Outcomes and Assessment Tools."

Expert participants came from 12 states and represented a variety of perspectives, based on personal and professional experiences, which greatly enriched the discussions. Participants included current or former general education or special education teachers, principals, school superintendents, parents of students with

disabilities, academics and researchers, assessment developers, think thank analysts, employees of state departments of education, and school board members. Representatives from the Council of State Governments, the Parent Teacher Association, and the U.S. Department of Education (ED) also participated.

Directly following the Experts Symposium, NCD hosted a town hall for people with disabilities in the Orlando area. NCD members heard from a number of parents of children and adults with disabilities, who expressed a grave disconnect between nonprofits, school systems, and state government agencies that provide services to people with disabilities and their families. Some expressed dismay that budget cuts often disproportionately affect people with disabilities and devastate their lives, giving voice to a widespread belief that short-term fixes should not be pursued without serious evaluation of the long-term consequences. NCD also heard from several service providers who summarized the services and supports their organizations offer, including parent training, transition services, group housing, and staffing services. They also identified barriers that hinder service delivery.

#### **Education Reforms**

Although significant achievement gaps persist between students with and without disabilities, as captured in the National Assessment of Educational Progress, disability advocates are quick to acknowledge the significant gains students with disabilities have made under NCLB/Elementary and Secondary Education Act (ESEA) due to a focus on subgroup accountability. As legislative and policy proposals emerge around ESEA reauthorization as well as assessment tools linked to the rollout of the Common Core State Standards,<sup>100</sup> reforms and envisioned "flexibility" should never compromise subgroup accountability.

#### **Common Core State Standards**

In June 2010, the National Governors Association Center for Best Practices and the Council of Chief State School Officers released the Common Core State Standards

(CCSS). These are common standards for all students in English/language arts and math designed to align with college and career expectations; internationally benchmarked; evidence-based; and focused on critical thinking, problem solving, and collaboration. The CCS have been adopted by 46 states to date, and are set for implementation by 2014.<sup>101</sup> With a greater focus on individualized learning needs, the CCSS include several affirmative statements on the necessity of instruction incorporating appropriate supports and accommodations for students with disabilities:

"The Standards should also be read as allowing for the widest possible range of students to participate fully from the outset and as permitting appropriate accommodations to ensure maximum participation of students with special education needs. For example, for students with disabilities reading should allow for the use of Braille, screen-reader technology, or other assistive devices, while writing should include the use of a scribe, computer, or speech-to-text technology. In a similar vein, speaking and listening should be interpreted broadly to include sign language."<sup>102</sup>

However, the CCSS have a caveat about items deemed outside their scope, while remaining resolute that all students must have the same opportunities to meet high standards:

"The Standards set grade-specific standards but do not define the intervention methods or materials necessary to support students who are well below or well above grade-level expectations. It is also beyond the scope of the Standards to define the full range of supports appropriate for English language learners and for students with special needs. At the same time, all students must have the opportunity to learn and meet the same high standards if they are to access the knowledge and skills necessary in their post-school lives."<sup>103</sup>

Since the release of the CCSS, attention has shifted to how the standards will be taught and assessed. In 2010, ED announced winners of the Race to the Top Assessment

competitive grants to develop a "new generation of tests" in mathematics and English Language Arts/Literacy aligned with the CCS.<sup>104</sup>, Winners include the Partnership for Assessment of Readiness for College and Careers (PARCC), a 26-state consortium with Florida as fiscal agent and Massachusetts as board chair; and the SMARTER Balanced Assessment Consortium (Smarter Balanced), a 31-state consortium with Washington state as both fiscal agent/board chair.<sup>105</sup> At the time of the announcement, ED Secretary Arne Duncan stated that the assessments developed around the CCSS will be designed from the start to assess students with disabilities, rather than retrofitting the assessments. Following the announcement, ED officials confirmed that there will be no need for alternate assessments based on modified achievement standards for students with disabilities (commonly referred to as the "2 percent tests"); however, the so-called "1 percent assessment," used with students with the most significant cognitive disabilities, will be aligned to the CCSS through a separate assessment development competition.<sup>106</sup> According to a May 2012 ED press release, the new assessment systems are on track for implementation in the 2014–15 school year.<sup>107</sup>

While having to wait to review the general assessments under development and the 1 percent assessment yet to be developed, one disability group aptly summarized many of the other unresolved questions for students with disabilities this way: "Will the CCSS change what special educators need to know? Will the CCSS lend themselves to modifications for learning profiles without minimizing expectations? How will important access and transition skills be integrated into the teaching schedule?"<sup>108</sup> Although these and other questions persist, the CCS Initiative insists that promoting a culture of high expectations is a goal for all students, including those with disabilities. Accordingly, the CCSS Initiative states that students with disabilities may be provided additional supports and services, such as instructional supports based on Universal Design for Learning, instructional accommodations. assistive technology, and other supports and services that "ensure that students receive access to multiple means of learning and opportunities to demonstrate knowledge, but retain the rigor and high expectations of the Common Core State Standards."<sup>109</sup>

In April 2012, NCD participated in a Council of State Governments focus group meeting on "Deeper Learning"<sup>110</sup> to explore how instruction, assessments, accountability, teacher and leader effectiveness, and technology should change to increase students' economic opportunities and civic engagement through education. NCD will continue to contribute to these and other policy discussions surrounding the CCSS as opportunities arise.

#### Recommendations

NCD recommends:

2.1 The adoption of the Common Core State Standards by most states provides a unique opportunity to improve access to the general curriculum through the principles of Universal Design for Learning and differentiated instruction. Schools should improve meaningful access to the general curriculum for all students, and state and federal policymakers should reject policies that exempt students from standardized testing on the basis of their disabilities.

# **Charter Schools**

Approximately 5,000 publicly funded, privately run charter schools across the country operate apart from the conventional public school system and are administered independently under a contract, often with a public school board. The contract typically articulates each school's unique mission, goals, success metrics, and modes of assessment.<sup>111</sup> Charter schools are regulated and financed quite differently from state to state. They are afforded a great deal of autonomy in the name of innovation and competition, but because many operate outside a traditional framework, they are ill equipped to serve students with disabilities, which in turn creates a loophole decried by many disability advocates.

Policy discussions have begun to focus intently on whether and how well the charter school movement is being held accountable for students with disabilities. Accountability for the performance of each student with a disability is a requirement under both IDEA and ESEA. State laws can grant charter schools flexibility in meeting state or local education regulations or policies, but charter schools must comply with all federal laws that apply to any other public school.<sup>112</sup>

However, because charter schools do not design a comprehensive plan to educate students with disabilities as school districts do, the Individualized Education Plan (IEP) of a student with a disability will likely deter that student from attending a charter school, which views it as an inappropriate placement because it has not been set up to implement IEPs and serve students with disabilities.<sup>113</sup> As a striking example of this phenomenon, a recent analysis of K–12 data on students with disabilities in 14 school districts in Florida, which represent more than three-fourths of Florida's total charter enrollment, revealed the following information about students with significant disabilities (including students with Down syndrome, cerebral palsy, and autism):<sup>114</sup>

- More than 86 percent of those charter schools do not serve even one student with a significant disability compared to more than half of school districts that do.
- In a school district that serves more than 1,000 students with significant disabilities, only one was enrolled in a charter school.
- There are no students with significant disabilities in charter schools in the 24<sup>th</sup>largest school district in the country.
- Most students with significant disabilities are enrolled in charter schools that specialize in particular disabilities.<sup>115</sup>

Since under federal law every eligible student with a disability is entitled to a free, appropriate public education in the least restrictive environment, publicly funded charter schools should not create separate or segregated schools for students with disabilities. NCD recognizes a role for state policies on charter schools in the education reform movement, including school choice. At the same time, such schools should comply with federal provisions that protect the rights of children with disabilities to be educated in the least restrictive environment. Charter schools are public schools and bear responsibility to make a free, appropriate public education available to all students with disabilities. Charter schools need to be open and available on an equal basis to all students, without segregation.

#### Recommendations

- 2.2 Ensuring that students with and without disabilities will learn side by side is the cornerstone of inclusive, integrated education. Developing, emphasizing, or launching disability-specific or segregated charter schools for students with disabilities runs contrary to the social, civic, and educational advances ensured by the Individuals with Disabilities Education Act and other seminal education reforms. Education must move forward, not return to the failed segregation practices of decades past.
- 2.3 Congress should amend IDEA to ensure the guarantee of a free and appropriate public education in the least restrictive environment (LRE) for students with disabilities attending charter schools. In particular, Congress and the U.S. Department of Education should clearly communicate that schools oriented around specific disabilities or segregated on the basis of disability status violate the LRE rights of students with disabilities. Furthermore, IDEA must clearly mandate that the obligation to provide free appropriate public education, including related services and identification of children with disabilities, is not diminished for charter schools, including charter schools acting as their own local education authority.

2.4 Congress should amend the Elementary and Secondary Education Act to put in place clear standards for charter school authorizers.

#### Vouchers

A recent publication reported that nearly 30,000 students with disabilities in eight states across the country use vouchers or scholarships to attend private schools with programs specifically designed for children with special needs.<sup>116</sup> These school choice programs exist in Arizona, Florida, Oklahoma, and Utah, with Arizona, Florida, Georgia, Louisiana, North Carolina and Ohio, (Arizona and Ohio each operate two programs. .<sup>117</sup> Vouchers and "school choice" scholarships are a method of education finance, paid for by public (and sometimes private) dollars, by which families are given a tuition certificate to apply toward attending a participating private school. Vouchers allow parents maximum choice in deciding how the public money for their students' education will be spent. Eligibility for vouchers depends on such things as disability, a family's income level, and the failure of the home school.

For nearly a decade, NCD has considered the effect of school vouchers on the experiences and outcomes of students with disabilities<sup>118</sup> and has elevated several areas of concern. Chief among these is that once students with disabilities use a voucher to attend a private school, they and their family relinquish rights under IDEA, including a parent's right to participate in meetings about his or her child's education and in hearings about how and whether a school is meeting a student's educational needs.

In addition, the dollar amount of vouchers frequently covers only a portion of costs associated with special education, which can leave a large amount of the private school tuition unaccounted for. This may have the effect of excluding lower-income families who may not be able to supplement remaining costs. In addition, and as recent reports continue to find, some private schools have policies or reputations for not accepting students with the most significant disabilities, which further marginalizes certain students with disabilities.

Finally, there has not been a demonstrable commitment to the IDEA principle of accountability for results. In fact, the nation's largest organization promoting "school choice" programs recently compiled data on accountability provisions in existing special education school vouchers programs, and the header of "academic accountability," broken into "standardized assessment," "public reporting of results," and "independent evaluation," indicated that none of the nation's special education voucher programs had any public reporting of results or independent evaluation, and only two (and one with a caveat) had any standardized assessment.<sup>119</sup>

#### Recommendations

- 2.5 Some states currently offer or are considering providing publicly funded vouchers or scholarships to students with disabilities to help pay private school tuition. Receipt of public funds, vouchers, or scholarships should not require students with disabilities to surrender their rights under the Individuals with Disabilities Education Act or the Americans with Disabilities Act. Schools that receive public funds should be required to publish assessment scores, graduation rates, and other outcome data of students with disabilities. Vouchers should not be used to create a publicly financed (in whole or in part) segregated educational system for students with disabilities.
- 2.6 The U.S. Department of Education and the U.S. Department of Justice should issue a letter to clarify civil rights violations that may be linked to creating a publicly financed (in whole or in part) segregated educational system for students with disabilities; vouchers should not be usable for schools segregated on the basis of a specific disability or disability status more generally.

# **Elementary and Secondary Education Act (ESEA)**

# No Child Left Behind Waivers

After the U.S. Department of Education (ED) announced its intention to offer waivers to states for key provisions of NCLB<sup>120</sup> in return for state adoption of various college- and career-ready standards and teacher evaluations, NCD met with key ED leaders, including Secretary Arne Duncan and Assistant Secretary for Special Education and Rehabilitative Services Alexa Posny, as well as staff in the Senate Health Education Labor and Pensions Committee, to discuss the development. Following those meetings, NCD issued a letter to Secretary Duncan supporting "flexibility for reform" in principle, but asked ED to ensure that the flexibility not compromise the accountability provisions, teacher quality provisions, and data partitioning under which students with disabilities have made great strides under NCLB.<sup>121</sup> In February 2012, ED updated "ESEA Flexibility – Review and Guidance"<sup>122</sup> available on its Web site, for states and reviewers considering waiver applications. NCD commends ED for sharing this information, which addresses the impact of proposed waivers on students with disabilities if waivers are granted.

As of the time of the writing of this report, 11 states had been granted waivers in the first round of applications, and 26 additional states had submitted applications for the second-round consideration.<sup>123</sup>

#### Recommendations

NCD recommends:

2.7 Congress should ensure that any revisions, repeals, or amendments to the Elementary and Secondary Education Act refrain from removing safeguards provided consistently with civil rights laws such as the Individuals with Disabilities Education Act, Section 504 of the Rehabilitation Act, and the Americans with Disabilities Act.

- 2.8 Congress and the U.S. Department of Education should look to the ESEA reauthorization process and the ESEA Flexibility Waiver process as an opportunity to promote methodologies, such as Universal Design for Learning, that expand access to the general education curriculum for students with and without disabilities.
- 2.9 Congress should ensure that students with disabilities are fully included within ESEA's accountability infrastructure, moving to eliminate the 2 percent modified assessment category and reform the 1 percent alternative assessment category.

#### Addressing Disparities in Underserved Populations

A number of underserved subgroups within the population of students with disabilities often experience discriminatory policies and practices in compounded ways. Such subgroups include, but are not limited to gender, racial, ethnic, and language minorities, and students with disabilities in the foster care system. NCD has a long-standing policy of outreach to diverse people with disabilities, through forums, quarterly meetings, and opportunities to provide written comments. NCD has a record of extending invitations and receiving stakeholder input on issues affecting underserved children and youth.<sup>124</sup>

According to a previous NCD report,<sup>125</sup> a considerable number of children and youth in the foster care system have disabilities and other diverse characteristics. In November 2011, as part of the implementation of the Fostering Connections to Success and Increasing Adoptions Act of 2008,<sup>126</sup> ED and HHS convened a summit titled "Child Welfare, Education and the Courts: A Collaboration to Strengthen Educational Successes of Children and Youth in Foster Care."<sup>127</sup> Its goal was to encourage

educational stability and improve educational outcomes for children in foster care. State teams composed of education, child welfare, and judicial branches participated and were charged with creating a plan for cross-system collaboration.<sup>128</sup>

# **Bullying Prevention**

All students, with and without disabilities, who experience bullying are familiar with the negative emotional, educational, and physical consequences.<sup>129</sup> However, students with disabilities are often disproportionately affected by bullying. Despite this, there is little research and policy specifically focused on the elimination of bullying of students with disabilities. Much of the current data specific to bullying of students with disabilities is collected at the state or local level, and the picture it paints is a disturbing one of frequent and targeted bullying. The 10 studies that have been conducted in the United States specific to bullying of students with developmental disabilities all found that such students were two to three times more likely to be bullied than students without developmental disabilities.

Students with disabilities must be included on an equal basis with other protected classes in bullying prevention efforts undertaken as part of general education laws and policy initiatives.<sup>131</sup> This includes policy discussions regarding the impending reauthorization of ESEA as well as bullying prevention efforts of the Health Resources and Services Administration and the ED Office for Civil Rights. In addition, it is necessary to consider utilizing the IEP process as well as IDEA's guarantee of a free and appropriate public education in the least restrictive environment to strengthen and increase ant bullying measures.

NCD commends ED and HHS for their March 30, 2012, announcement about the revitalization of a collaborative Web site for bullying prevention. The enhanced Web site (<u>www.stopbullying.gov</u>) with suggested action steps was a joint agency response to the March 2011 White House conference on Bullying Prevention in which NCD participated and the September 2011 Partners in Bullying Prevention Summit. NCD is co-hosting the third annual Federal Partners in Bullying Prevention Summit August 6–7, 2012, spear-

headed by the U.S. Department of Education's Office of Safe and Healthy Students, in conjunction with the departments of Justice, Health and Human Services, Defense, Agriculture, the Interior, the Federal Trade Commission, and the White House Initiative on Asian Americans and Pacific Islanders.

### Recommendations

- 2.10 All federal agencies should include disability in their data collection on bullying, victimization, violence, harassment, and hate crimes.
- 2.11 Congress should consider supplementing existing nondiscrimination laws, such as the Americans with Disabilities Act, Title IX, and the Civil Rights Act of 1964, with an explicit private right of action aimed at holding schools accountable for severe, persistent, and pervasive bullying and harassment.
- 2.12 The U.S. Department of Education should include the Equal Employment Opportunity Commission as a critical stakeholder in federal bullying prevention efforts and issues surrounding workplace bullying.
- 2.13 The U.S. Department of Justice and the Federal Bureau of Investigation should work collaboratively on fighting hate crimes against people with disabilities in all settings.
- 2.14 Congress should include in the Elementary and Secondary Education Act reauthorization and other applicable laws and procedures a requirement that parents be notified when their child is either victim or perpetrator in an incident of bullying or harassment.

2.15 ED's Office of Special Education and Rehabilitative Services should expand technical assistance on how to utilize the Individualized Education Plan to protect students with disabilities from bullying and harassment and effective ways to address bullying behaviors that may be linked to a disability.

#### Seclusion, Restraints, and Aversives

The use of seclusion, restraints, and aversives in educational settings has received increased national attention in recent years and rightly continues to galvanize the disability community. Families and local news reports frequently cite chilling accounts of students with disabilities being choked, confined, pinned down, or otherwise hurt by adults they are supposed to trust.

While unable to determine whether allegations were wide spread, Congressional testimony of the U.S. Government Accountability Office (GAO) in 2009 cited hundreds of cases of alleged abuse and death tied to seclusion and restraint methods used on students in public and private schools and in treatment centers.<sup>132</sup> The testimony also noted that no federal agency or other entity seems to collect information on the incidence of seclusion and restraint and its effects, nor do the states uniformly restrict the practice.<sup>133</sup> Alarmingly, thorough examination of several cases showed patterns of parents not being aware of nor giving consent to the practices used on their children; children who received these punishments not having displayed physical aggression prior to receiving them; and a lack of consequences for teachers who used these practices.<sup>134</sup> Following the GAO report and a number of disability groups keeping focused attention on the topic at the federal level through reports and advocacy, bipartisan legislation<sup>135</sup> was introduced in the last Congress that eventually passed the House but did not pass the Senate. Similar legislation has been reintroduced<sup>136</sup> in both the House and the Senate in the 112<sup>th</sup> Congress.

Shortly after the 2009 heightened attention to the topic in Congress and elsewhere, ED Secretary Arne Duncan wrote the Chief State School Officers, urging them to review and revise or develop state policies regarding restraint and seclusion.<sup>137</sup> A short time later, ED wrote the original sponsors of the legislation from the 111<sup>th</sup> Congress and shared a number of principles it believed Congress should consider in legislation, <sup>138</sup> including an emphasis on data collection. In March 2012, summary data captured during the 2009-2010 academic year in ED's Civil Rights Data Collection (CRDC) shows that while students with disabilities represented only 12 percent of the students in the CRDC sample,<sup>139</sup> they constituted 69 percent of the students physically restrained by adults in their schools.<sup>140</sup> The summary data shows that of the total 38,792 students represented who were subject to physical restraint, 26,766 of them, were students with disabilities.<sup>141</sup> When the data is further parsed for demographic subpopulations, additional disparities emerged. For instance, while African-American students represent 21 percent of students with disabilities overall, they constitute 44 percent of students with disabilities subjected to mechanical restraints.<sup>142</sup> Even though the more comprehensive data report had not been released as of the time of the writing of this report, this data clearly shows that claims of the incidence of seclusion and restraints and its disparate use on students with disabilities are not merely anecdotal, and that calls for decisive action from ED and Congress are not baseless.

The use of aversive "treatments" has also gained great public attention in the past year, with media attention focused on the use of electric shock and other aversive techniques on students with disabilities by the Judge Rotenburg Center (JRC) in Canton, Massachusetts, a residential school for students with disabilities. NCD has a long history of opposition to aversive treatments<sup>143</sup> as contrary to the letter and spirit of the ADA and the DD Act, and at odds with findings of mental health and developmental disability research.<sup>144</sup> The use of aversive measures on people without disabilities is already recognized as illegal and immoral.

The Massachusetts Department of Developmental Services recently adopted regulations that greatly restrict the use of intentional pain as a form of treatment, by

preventing the use of contingent electric shock for new students entering JRC, but JRC is still permitted to use aversive treatment on students with disabilities who were previously admitted. NCD views the issue as one of national importance, because students from multiple states and the District of Columbia attend JRC and are potentially subject to such treatment. In April 2012, NCD sent a letter to DOJ's Disability Rights Section of the Civil Rights Division, urging DOJ to expedite its investigation of JRC and issue its findings.<sup>145</sup>

NCD commends the Senate HELP Committee chaired by Senator Harkin for its July 2012 public hearing on seclusion and restraint. Along with other stakeholders, NCD looks forward to follow-up congressional actions that promote positive behavior and environments for all students.<sup>146</sup>

#### Recommendations

NCD recommends:

- 2.16 Congress should act swiftly to pass S. 2020/H.R. 1381, the Keeping All Students Safe Act.
- 2.17 The Department of Justice should move swiftly to follow up on its open investigation of the Judge Rotenberg Center and work to close the facility, ending contingent electric shock for existing students as well as supporting the state's ban on the practice for incoming students.

#### Youth Transitions

A 2010 policy publication, *Future of Children,* states that the most important markers of adulthood are now considered to be completing school, establishing an independent household, and being employed full time.<sup>147</sup> Yet the sparse data available on people

with disabilities indicates that many of them have less success with those markers. During a decade-long longitudinal study (1999–2009), the high school dropout rate remained high across all youth, including students with disabilities. However, the percentage of high school dropouts in 2009 among 16- to 24-year-olds with disabilities was twice as large (15.5 percent) as that of their peers without disabilities (7.8 percent).<sup>148</sup> Because the markers of establishing an independent household and being employed full time seem conjoined, NCD's recommendation to blend federal funds for coordinated service delivery, first introduced in 2010, warrants restatement.<sup>149</sup>

#### Recommendations

- 2.18 Congress should authorize and mandate the development and implementation of coordinated serve delivery approaches specifically targeted to transitioning youth with disabilities that are based on "blending" of funds (e.g., Vocational Rehabilitation, other Workforce Investment Act programs, special education, postsecondary education, Veterans Administration, Social Security Administration, and other appropriate funding agencies).
- 2.19 Congress should pass the TEAM (Transitioning toward Excellence, Achievement and Mobility) Acts (H.R. 602, 603, and 604) aimed at developing a comprehensive national infrastructure to support the transition of youth with significant disabilities.

# **Higher Education Act**

#### Accessible Instructional Materials

In 2011, NCD served on the National Commission on Accessible Instructional Materials for Postsecondary Students with Disabilities (AIM). Per the Higher Education Act (reauthorized in 2008), ED convened the body and served as lead agency.<sup>150</sup> The AIM Commission's charge was to study the state of accessible materials for students with disabilities in postsecondary education and make recommendations to the ED secretary and the relevant authorizing committees in Congress. The AIM Commission's December 2011 report offers pointed considerations for improving access to and distribution of instructional materials in accessible formats.<sup>151</sup>

#### Recommendations

- 2.20 Congress should authorize the United States Access Board to establish guidelines for accessible instructional materials that will be used by government, in the private sector, and in postsecondary academic settings.
- 2.21 Congress should consider incentives to accelerate innovation in accessibility by publishers and producers of course materials, hardware, and software by offering support and inducements for the production, sale, and consumption of accessible instructional materials and delivery systems.

2.22 NCD supports the Accessible Instructional Materials Commission's recommendations for federally sponsored projects and programs to help postsecondary faculty and staff become educated about the delivery of high-quality accessible instructional materials to meet the needs of students with disabilities in postsecondary settings.

## Inclusion of Students with Intellectual Disabilities in Higher Education

NCD applauds the ED and HHS-funded initiatives now under the umbrella of "Think College" to assist students with intellectual disabilities and their families around the country. Think College began as a demonstration project and has expanded its work in areas of research, training and technical assistance, and information dissemination.<sup>152</sup> The collaborative efforts bring together four initiative that support people with intellectual disabilities in gaining access and succeeding in inclusive postsecondary education (e.g., two-year or four-year college, vocational training) institutions.<sup>153</sup>

#### Recommendations

NCD recommends:

- 2.23 The U.S. Department of Education, Office of Civil Rights should expand enforcement, guidance, and technical assistance activities aimed at securing the rights of students with disabilities in higher education, placing emphasis on students with disabilities whose protections were restored by the Americans with Disabilities Amendments Act.
- 2.24 Congress and ED should maintain and expand funding for inclusive higher education programs for students with intellectual disabilities.

# CHAPTER 3. Earning

# Introduction

More than two decades after the passage of the ADA, the unemployment rate for Americans with disabilities stubbornly remains nearly double that of people without disabilities, while their rate of labor force participation has continued to be abysmally low. The latest figures from the Bureau of Labor Statistics (BLS) show that labor force participation for workers with disabilities was 20.3 percent, while the total for workers without disabilities was 69.1 percent—more than three times higher.<sup>154</sup> As of April 2012, the unemployment rate for people with disabilities was 12.5 percent, versus 7.6 percent for those without disabilities.<sup>155</sup>

Clearly, much more work is needed to realize the goals of the ADA regarding employment for people with disabilities. People with disabilities, particularly those with the most significant disabilities, need flexible supports to enter the workforce and thrive at the same level as peers without disabilities. Furthermore, it is imperative that more consideration be given not just to increasing the employment of people with disabilities, but also to promoting quality employment in terms of wages, mobility, and settings.

## **Employment Discrimination Claims**

NCD commends the Equal Employment Opportunity Commission (EEOC) for demonstrating commitment to vigorous enforcement of the ADA, as amended. The agency reports filing and resolving 80 enforcement suits with ADA claims in fiscal year (FY) 2011, to ensure fair and equal treatment of all people with disabilities in the workplace.<sup>156</sup> In light of the ADA Amendments Act (ADAAA), discrimination claims brought by people with disabilities are now substantially more likely to focus on whether or not discrimination occurred, rather than whether or not the person bringing the claim qualifies as a person with a disability. Thus, both EEOC and private litigants are able to

conduct more enforcement activities aimed at previously underserved groups of people with disabilities, such as people on the autism spectrum, people with traumatic brain injury, and other groups with less visible disabilities who may have struggled to "prove" themselves as disabled prior to the ADAAA.

# Impact of the Recession

Although states are increasingly reporting a steady and slow return to fiscal stability, many had to cut critical supports and services relied upon by people with disabilities. Some 2012 state budgets, most of which went into effect in July 2011, included cuts to health care for people with disabilities, to personal attendant services hours, to state cash assistance for people with disabilities, to transportation services, and to affordable housing programs. Although many of the cuts may not appear to affect employment, many services are critical supports that people with disabilities rely on to become or remain taxpayers.<sup>157</sup>

# **Social Security Disability Programs**

The Social Security Administration (SSA) has important, long-established work incentives that allow Supplemental Security Income and Social Security Disability Insurance beneficiaries to earn income without risking loss of benefits while working toward a future occupational goal or maintaining self-employment and small business ownership. However, agency personnel and service provider agency staff, as well as beneficiaries, remain relatively unfamiliar with the Plans for Achieving Self-Support program and the Benefits, Planning, Assistance and Outreach program. For these programs to have any widespread or lasting impact, SSA should embark on a major public awareness, outreach, education, and technical assistance campaign. In addition, these programs preclude savings for nonemployment-related purposes and are perceived as being complex and bureaucratic. Thus, although SSA has taken steps to improve its return-to-work services through the provision of work incentives, these efforts are hampered by the underlying program rules that were designed for people assumed to be permanently retired and people who were viewed as unable or unlikely to work in the future.

# Recommendations

NCD recommends:

3.1 Congress should direct the Social Security Administration, the Center for Medicare & Medicaid Services, the U.S. Department of Housing and Urban Development, and the U.S. Department of Labor's Employment and Training Administration to develop and implement an expanded, integrated benefits planning and assistance program that coordinates resources and oversight across several agencies, enabling beneficiaries, including those transitioning out of sheltered workshops, to access benefits planning services within multiple federal systems. SSA should also make changes to the existing system to improve the accuracy and quality of services provided to individual beneficiaries.

# **Employment Disparities among Subgroups**

The disability community has long pointed out the many benefits of employment—work enhances skills such as communication, socialization, academics, physical health, and community skills; it factors into how one is perceived by society; it promotes economic well-being; it leads to greater opportunity for upward mobility; and it contributes to greater self-esteem.<sup>158</sup> Yet for many subgroups of people with disabilities, even more so than the group as a whole, those benefits of employment are rarely experienced. Eight out of ten people with intellectual and developmental disabilities are not in the labor market,<sup>159</sup> and only 15 percent of those with a psychiatric disability are.<sup>160</sup>

The Administration has focused recently on the employment of people with targeted disabilities. NCD commends EEOC for its efforts to call attention to unmet needs in employment among people with mental disabilities. EEOC hosted a meeting on March 15, 2011 focused on people with intellectual disabilities and psychiatric disabilities.<sup>161</sup>

Unfortunately, the definition of targeted disability has not been revised for a considerable time and is in need of updating to reflect emerging disability categories.

NCD partnered with the U.S. Department of Labor (DOL), Office of Disability Employment Policy (ODEP) in preparation for its August 2011 "Add Us In"<sup>162</sup> national forum, to help frame the "Culture and Identity" session. Add Us In is an ODEP initiative to develop strategies to increase employment of people with disabilities within small businesses, which are at the heart of economic growth. The national event brought together people with disabilities from diverse racial, ethnic, and gender groups to create a blueprint for disability hiring in the small business sector. They discussed the national implications of Add Us In and supported the creation of the national network necessary for collaboration, dissemination, and implementation of successful policies and practices. Focus areas also included cultural and linguistic competence within employment systems to address a variety of targeted business and populations.

#### **Workforce Investment Act**

The Workforce Investment Act (WIA) of 1998<sup>163</sup> was designed to provide a streamlined system of assistance that integrates many employment and training programs through a one-stop delivery system for employers and job seekers, including job seekers with disabilities. WIA is unique in its capacity to serve people with disabilities who desire employment assistance, both in terms of overcoming common barriers to employment and promoting promising strategies, and improving service delivery to workers with disabilities.

A vote on the reauthorization of WIA was scheduled for August 2011 but was postponed indefinitely. Draft legislation and introduced bills on reauthorization have been discussed in both chambers of the 112<sup>th</sup> Congress, but at the time of the writing of this report, there is no clear timeline to move the legislation forward. WIA may not be addressed again until the 113th Congress.

The delay was partly caused by disagreements over a provision of the bill that would regulate when people with disabilities could work for less than the federal minimum wage. Some disability advocacy groups assert that the provision would protect a system of sheltered workshops that they fear lacks sufficient oversight and does not promote the desired outcome of competitive job training and integrated employment. NCD has conducted site visits around the country to get a detailed understanding of how employment programs work best and to identify the difficulties faced by workers with disabilities in gaining competitive integrated employment.

#### Recommendations

NCD recommends:

- 3.2 As part of reauthorization of the Workforce Investment Act, Congress should ensure the following:
  - Accessibility plans for all one-stop job delivery systems should meet requirements for vigorous and proactive enforcement of the antidiscrimination and accessibility requirements as established by the U.S. Department of Labor.
  - Accessibility plans should have measurable goals, timeframes, and methods for achieving and maintaining physical, communication, and program access.
  - State and local Workforce Investment Boards should develop plans with the participation of people with disabilities, with meaningful documentation of their involvement throughout the planning process and an account of how their comments and recommendations were incorporated into final plans.

3.3 Congress should establish an enhanced match for supported employment services in integrated employment settings within the Medicaid program.

# **Federal Hiring Initiative**

Executive Order (EO) 13548 that challenges the Federal Government to lead by example in improving the employment of people with disabilities, was signed and went into effect on July 26, 2010, the 20<sup>th</sup> anniversary of the ADA.<sup>164</sup> With the order, the President challenged federal departments not only to hire individuals with disabilities, but also to increase the rate at which workers with disabilities are retained and to advance specific benchmarks to be met over the course of five years.<sup>165</sup> On January 6, 2012, United States Customs and Border Protection became the first federal agency to establish a formal alliance with the DOL ODEP to advance opportunities for workers with disabilities.<sup>166</sup>

## Recommendations

NCD recommends:

- 3.4 All federal agencies need to increase hiring of employees with disabilities in accordance with Executive Order 13548. All Federal Government agencies need to develop and enact measurable outcome systems and ensure meaningful enforcement of stated goals.
- 3.5 The National Institute on Disability and Rehabilitation Research should solicit input on the importance of research and development of metadesign applications as part of its focus on universal design for all government-funded projects.

3.6 The Office of Personnel Management, working in collaboration with the Equal Employment Opportunity Commission, should revise the definition of "targeted disability" categories to reflect current needs and priorities and to incorporate disability categories whose underrepresentation in the workforce has become evident more recently, such as people on the autism spectrum and people with other developmental disabilities.

#### Federal Employment of Veterans with Disabilities

Notwithstanding recognition of the efforts identified in this report, much work remains to be done across the Federal Government for returning veterans. In 2009, President Obama issued EO 13518, "Employment of Veterans in the Federal Government," which created the Veterans Employment Initiative to recruit, train, and retain veterans as civilian employees in the Federal Government, and contained several specific provisions to assist veterans with disabilities.<sup>167</sup> When President Obama signed federal legislation in November 2011, tax credits were granted to companies that hire unemployed veterans.<sup>168</sup> Although this is a positive temporary incentive, permanent solutions are needed.

Preliminary data available at the time of the writing of this report shows disappointing detailed figures, despite an increase of 4.5 percentage points for veteran federal hires in the first half of FY 2011 compared with the same period in FY 2010.<sup>169</sup> One in three new Federal Government hires in the first half of FY 2011 was a veteran.<sup>170</sup> However, that data is not disaggregated to indicate how many of the new hires were veterans with disabilities.

# Recommendations

NCD recommends:

- 3.7 Congress should make permanent the tax breaks for businesses that hire veterans.
- 3.8 The President should assign a Cabinet-level head or designee to coordinate veterans disability policy efforts across federal agencies to increase the hiring of veterans with disabilities who need appropriate supports and services.

# Federal Contractors and Subcontractors Hiring Workers with Disabilities

Section 503 of the Rehabilitation Act of 1973 prohibits discrimination against people with disabilities and requires employers with federal contracts or subcontracts that exceed \$10,000 to take affirmative action to hire, retain, and promote qualified individuals with disabilities.<sup>171</sup> All covered contractors and subcontractors must also include a specific equal opportunity clause in each of their nonexempt contracts and subcontracts.<sup>172</sup> This law is enforced by the Employment Standards Administration's Office of Federal Contract Compliance Programs (OFCCP) within the DOL.<sup>173</sup>

On February 6, 2012, NCD sent a letter to Debra Carr, director, Division of Policy, Planning and Program Development at OFCCP. The letter supports modernization of Section 503 regulations, the 7 percent target goal established for federal contractors, and the incorporation of disability categories into the Final Rule so the disability community can benefit fully from its new affirmative action. At that time, NCD also asked that subcontractors in sheltered workshop settings not be counted toward a contractor's affirmative action obligations under Section 503, even if such workshops are considered training programs. This is vital so that the goals of competitive integrated employment are met.

# Recommendations

NCD recommends:

- 3.9 In the interest of the goals of competitive integrated employment, subcontractors in sheltered workshop settings should not be counted toward a contractor's affirmative action obligations under Section 503 of the Rehabilitation Act, even if such workshops are considered training programs.
- 3.10 The Office of Federal Contract Compliance Programs should establish a hiring subgoal for federal contractors to hire people within a targeted disability category as part of their Section 503 affirmative action obligations.

# Veterans

"Economic opportunity for today's war-fighters is a national imperative that continues to demand the kind of decisive action we saw with last year's [2011] passage of the VOW to Hire Heroes Act. Recent unemployment numbers indicate that veterans of the current conflicts [Iraq and Afghanistan] remain unemployed at a higher rate than their civilian counterparts, with young veterans and female veterans experiencing unemployment rates well over twice the national average." (Ryan M. Gallucci, Deputy Director, National Legislative Service, Veterans of Foreign Wars of the United States)<sup>174</sup>

# Veterans with Disabilities' Unemployment Figures

The available unemployment data for all veterans was compiled and reported by the Bureau of Labor Statistics (BLS). At the writing of this report, the BLS data reported in

2010, <sup>175</sup> 2011, and 2012 specifically separates unemployment rates for veterans with disabilities from the overall veterans' data. A pattern shows unemployment rates are higher for veterans with service connected disabilities than for the general population of veterans across various wars. For example, among the 1.4 million veterans disabled in World War II, the Korean War, and the Vietnam era, 28.8 percent were in the labor force in August 2009, compared with 37.0 percent of veterans from these periods who did not have a service-connected disability. The August 2011 unemployment rate for veterans with a service-connected disability was 8.5 percent compared to 7.9 percent for veterans with no disability. <sup>176</sup> Gulf War-era II veterans with a disability had a 12.1 percent rate of unemployment which was higher than the 9.5 percent for those without a disability. While the BLS reports show that there is no statistical significance in the figures, the differences for some veterans and their families are real and meaningful.

## **Congressional and Executive Branch Action**

What is being done to remedy the situation? Generally, oversight responsibilities can make a difference for all veterans, and NCD acknowledges ongoing congressional and federal agency work to address some of the unique needs of veterans with disabilities. Full and subcommittee hearings on various laws have provided information on what is needed for a seamless transition from military service to civilian life. NCD calls attention to several actions affecting disability compensation, vocational rehabilitation, and education that are linked to employment and earning. NCD applauds the positive congressional action in passing the Veterans Opportunity to Work Act of 2011. Among its provisions are the following:

- 1. Retraining assistance for certain 35- to 60-year-old veterans;
- 2. Revised guidelines for the Transition Assistance Program regarding counseling, employment, and training services, including required participation;
- 3. Modifications to the transition of veterans to civilian employment;

- 4. Improvements in providing information to veterans about their rights under the Uniformed Services Employment and Reemployment Rights Act—in many cases, the outcomes are seen in the enhanced employment options for service members who lost jobs due to the downturn in U.S. economy or to a serviceconnected disability; and
- 5. Other matters affecting earning/economics for veterans with disabilities, such as home financing and pension limits for veterans residing in nursing homes paid through Medicaid. Each provision also calls for specific evaluation or assessment and reports to Congress of how the components are working to benefit veterans.

November 2012 will mark three years since Executive Branch leaders were directed to carry out President Obama's Executive Order on Employment of Veterans in the Federal Government (EO 13518). The order also established a Council on Veterans Employment co-chaired by the secretaries of Labor and Veterans Affairs and the director of the Office of Personnel Management as vice chair.

While NCD recognizes several initiatives aimed at combatting the high unemployment of veterans in general, greater attention will need to be given the outcomes for veterans with disabilities. Among those initiatives are: (1) the November 2011 executive action taken by President Obama and the related action by DOL and the VA , including an online Veteran's Gold Card entitles post-9/11 veterans to free career counseling at any DOL career center for six months; (2) the Mil2Feds launched in May 2011 (putting it into the previous fiscal year), as the first and much-needed military occupation to federal occupation translator which matches veterans' military occupations to a civilian jobs database;<sup>177</sup> (3) changes in the National Defense Authorization Act (NDAA) to allow participation in apprenticeships and internships that support transition to the civilian world.<sup>178</sup> However, not all units are located near abundant federal opportunities; and (4) DOL's for reassessment of its employment opportunities and commends the collaborative efforts of DoD, the VA, DOL, and the Department of Homeland Security to improve transition outcomes for service members, including people with disabilities.<sup>179</sup>

"Our veterans have made sacrifices on behalf of the nation, and I ask all employers to renew their commitment to veterans, because the best way to honor our veterans is to employ them. No veteran should have to fight for a job at home after fighting to protect our nation."

—Secretary of Labor Hilda L. Solis, March 20, 2012)<sup>180</sup>

A related Department-level initiative is DOL's "Hiring Vets Toolkit,"<sup>181</sup> designed to assist and educate employers who have made the proactive decision to include transitioning service members, veterans, and wounded warriors in their recruitment and hiring initiatives. Key elements for employers include information on how to (1) create a culturally sensitive new hire orientation plan, (2) understand their responsibilities under the ADA, (3) consider disclosure concerns, and (4) know where to obtain free, one-onone guidance on job accommodations.

#### Recommendations

NCD recommends:

3.11 The secretaries of various service components (U.S. Armed Forces) should analyze the requirements for making internships available at state and local agencies. This would promote and support wellness opportunities for transitioning service members in wounded warrior units, including in rural and less populous areas of the United States.

#### Mental Health Impact on Earning and Economics among Veterans

Attention to mental health is sometimes considered the final frontier in health care, but public awareness about the needs and growing number of veterans with unseen disabilities reached a new level in 2011. In March 2012, Wounded Warrior Project (WWP) President Dawn Halfaker told a joint session of the House and Senate Veterans' Affairs committees, a survey revealed that 78 percent of warriors self-identified as having a mental health condition, 51 percent reported having experienced a traumatic brain injury, and one in three reported that mental health issues made it difficult for them to obtain employment or hold jobs. WWP's information shows that PTSD and other invisible wounds can affect a warrior's readjustment in many ways—impairing health and well-being, compounding the challenges of obtaining employment, and limiting earning capacity.<sup>182</sup>

The good intention of congressional actions to increase hiring of veterans sometimes is overshadowed by disjointed implementation efforts. Veterans are often unaware of available resources. Unemployment rates for veterans with and without disabilities remain higher than those of the general population. Attention to the impact of mental health issues on employment is needed. Federal agencies have made some progress, but can improve coordination to simplify information provided to service members and their families before and during transition from military to civilian living.

NCD commends DoD for supporting legislation extending through December 31, 2014, Section 1631 (b) (1) of the National Defense Authorization Act. Extending this benefit to service members with disabilities while they are still members of the Armed Forces helps them identify training requirements and resources needed to achieve their rehabilitation and employment goals. DoD continued its collaborative partnership with DOL's Veterans Employment and Training Service.

## Conclusion

The long-term fiscal stability of the United States of America depends, in part, on ensuring that Americans with disabilities have meaningful opportunities to contribute to our collective well-being and on eliminating outdated policies that keep people in cycles of poverty and dependency. The Federal Government must find ways to integrate the delivery of necessary supports and services across agencies to ensure effective coordination and collaboration that meet individual needs and agency goals. Effective implementation and enforcement of the ADA requires thorough, sustained monitoring, evaluation, and interagency collaborations to ensure that full civic and social participation, equal opportunity, independent living, and economic self-sufficiency are achievable for all Americans, including those with disabilities.

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<sup>4</sup> U.S. Department of Justice, "Justice Department Issues Further Guidance on Accessibility Requirements for Existing Swimming Pools at Hotels and Other Public Accommodations" (May 24, 2012). <u>http://www.justice.gov/opa/pr/2012/May/12-crt-673.html</u>.

<sup>5</sup> U.S. Department of Justice, "Justice Department Reaches Americans with Disabilities Act Settlement with Trinity Health Systems in Iowa" (March 30, 2012). <u>http://www.justice.gov/opa/pr/2012/March/12-crt-404.html</u>.

<sup>6</sup> U.S. Department of Justice, "Justice Department Settles with Mountain Valley, Pa., Midget Football League Under the Americans with Disabilities Act" (March 20, 2012). <u>http://www.justice.gov/opa/pr/2012/March/12-crt-345.html</u>.

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<sup>8</sup> U.S. Department of Justice, "Justice Department Reaches Settlement with Connecticut Early Learning Center to Ensure Equal Opportunity for Children with Autism" (June 28, 2011). <u>http://www.justice.gov/opa/pr/2011/June/11-crt-849.html</u>.

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<sup>11</sup> U.S. Department of Justice, "Remarks of Assistant Attorney General for Civil Rights Thomas E. Perez at His Installation Ceremony" (November 13, 2009). <u>http://www.justice.gov/crt/speeches/perez\_installation\_speech.php</u>.

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<sup>13</sup> U.S. Department of Justice, Office of Civil Rights, "Justice Department Obtains Comprehensive ADA Agreement Regarding the Commonwealth of Virginia's Developmental Disabilities System" (January 26, 2012). <u>http://www.justice.gov/opa/pr/2012/January/12-crt-111.html</u>.

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<sup>15</sup> U.S. Department of Justice, Civil Rights Division, Letter to State of Mississippi re: United States' Investigation of the State of Mississippi's Service System for Persons with Mental Illness and Developmental Disabilities (December 22, 2011). <u>http://www.justice.gov/crt/about/spl/documents/miss\_findletter\_12-22-11.pdf</u>.

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<sup>23</sup> American Council of the Blind, et al v. Henry M. Paulson, Jr., Secretary of the Treasury, Order and Judgment, United States District Court for the District of Columbia, Order and Judgment, Case 1:02-cv-00864-JR, Document 96, Filed October 3, 2008. http://moneyfactory.gov/images/order\_injunction.pdf.

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<sup>25</sup> U.S. Department of Treasury, Bureau of Engraving and Printing, "EyeNote® App Overview" <u>http://www.eyenote.gov</u>.

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<sup>32</sup> Streamlining Requirements Governing the Use of Funding for Supportive Housing for the Elderly and Persons With Disabilities Programs, Proposed Rule, 77 Fed. Reg. 18723-18731 (March 28, 2012) (to be codified at 24 CFR pt. 891).

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<sup>172</sup> Ibid.

<sup>173</sup> Ibid.

<sup>174</sup> Statement of Ryan M. Gallucci, Deputy Director, National Legislative Service, Veterans of Foreign Wars of the United States, Hearing Before the Veteran's Affairs Subcommittee on Economic Opportunity, U.S. House of Representative (March 8, 2012). <u>http://www.vfw.org/VFW-in-DC/Congressional-Testimony/HVAC-EO-Bill-Hearing/</u>.

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<sup>176</sup> BLS news Release: U.S. Department of Labor, Bureau or Labor Statistics Employment Situation of Veterans --- 2011 (March 20, 2012). <u>http://www.bls.gov/news.release/pdf/vet.pdf</u>.

<sup>177</sup> *Bloomberg BusinessWeek*, "Obama Said to Plan 'Gold Card' to Help Veterans Find Employment." <u>http://www.businessweek.com/news/2011-11-11/obama-said-to-plan-gold-card-to-help-veterans-find-employment.html</u>.

<sup>178</sup> Warrior Care Blog. Operation War Fighter Overview. <u>http://warriorcare.dodlive.mil/wounded-warrior-resources/operation/warfighter/</u>.

<sup>179</sup> Assistant Secretary of Labor for Vets Raymond Jefferson's Testimony before the Subcommittee on Economic Opportunity Committee on Veterans Affairs, U.S. House of Representatives (July 29, 2009). <u>http://www.dol.gov/\_sec/media/congress/</u>20100729\_Jefferson.htm.

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