2013 National Disability Policy:

A Progress Report: "Strength in Our Differences"

October 31, 2013

National Council on Disability

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

2013 National Disability Policy: A Progress Report: "Strength in Our Differences"

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

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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

October 31, 2013

President Barack Obama
The White House
1600 Pennsylvania Avenue, NW
Washington, DC 20500

Dear Mr. President:

Pursuant to its statutory mandate, the National Council on Disability (NCD) provides an annual report on the nation's progress in achieving the ADA goals of equality of opportunity, independent living, full participation and economic self-sufficiency for an estimated 57 million Americans with disabilities. NCD is pleased to present the *2013 Report on National Disability Policy: Strength in Our Differences.* This report highlights recent federal achievements from August 2012 to September 2013 and identifies areas where changes in public policy and additional steps are needed.

The report information results from its outreach to stakeholders—including people living with disabilities—and the analysis of data on indicators of the status of disability policy in federally funded programs and supports in the United States and abroad. NCD consulted with diverse voices from the broad disability community in determining its findings and their views provided the basis for its recommendations.

The report culminates in recommendations to improve federal collaborative efforts in ways which benefit people with disabilities and families, including the following:
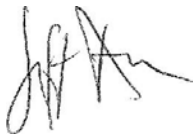
1. The 113th Congress should ratify the Convention on Rights of Persons (CRPD) with disabilities. CRPD offers a vital framework for other nations to create and enact legislation and policies that recognize and embrace the human rights and dignity of all people – including people with disabilities;

2. An Executive Order should be issued to create a federal interagency workgroup on financial incentives for full community participation and economic self-sufficiency for people with disabilities and their families, which includes the identification of policy barriers and efficient, consistent, coordinated, comprehensive, and consumer-friendly approaches;

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3. The Departments of Defense and Veterans Affairs, and other relevant federal agencies, are directed to coordinate in implementing secure, private, on-line information sharing for all veterans' health and benefit record —for the efficient provision and processing of each veteran's healthcare needs and to end the backlog of veterans; claims; The DOJ and DOT implement a Project Civic Access program targeting public transportation and paratransit systems that have high rates of complaints from local citizens for inaccessibility, for the purpose of bringing transportation providers into compliance; and

4. The US Election Assistance Commission and Research Alliance for Accessible Voting identify and provide technical assistance including small grant amounts to state and local governmental entities in high poverty areas to create accessible polling sites.

NCD appreciates the opportunity to present an independent and nonpartisan assessment of progress in national disability policy. As we approach the 25th anniversary of the ADA, NCD intends this annual report as a resource to support our nation's continuing progress toward achieving the four goals of the ADA
NCD stands ready to work with you, the administration, Congress and Americans to ensure that we realize the promise of the ADA for all of us.

Respectfully,

Jeff Rosen
Chairperson

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

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ACKNOWLEDGMENTS

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EXECUTIVE SUMMARY

The National Council on Disability (NCD) is privileged to present *Strength in Our Differences*, NCD's 2013 Progress Report summarizing the status of federal laws and programs serving an estimated 57 million Americans with disabilities, their families, and the diverse segments of the disability community in fulfillment of NCD's statutory mandate to annually report and make recommendations concerning the state of disability policy in the United States. Consistent with the tradition begun in NCD's seminal report from 1986, *Toward Independence: An Assessment of Federal Laws and Programs Affecting Persons with Disabilities,* the 2013 Progress Report is derived from the diverse voices of the disability community, including interviews with knowledgeable consumers, advocates, and experts on disability programs, supports, and services from across the nation.

The title, *Strength in Our Differences*, symbolizes the diversity of experiences and abilities within the US disability community, consistent with the diversity of experiences and abilities among all Americans. *Strength in Our Differences* also represents the fact that as a nation we are stronger, and as a people we are more able to respond to the challenges in the ever-changing world that we share, because of our diversity.

In preparing this report, NCD sought a cross-section of views from the diverse disability community. NCD conducted outreach to different populations within the disability community including parents, those seeking to be parents, veterans, youth and young adults with disabilities from diverse cultures, as well as family members and service providers. Several people interviewed fit more than one of these designations. Interviews were conducted by telephone, in person, through video systems, and by print communication.

The interview process was designed to capture the lived experience of participants, through their responses to the guiding question: *"What do you think is the single most important public policy issue for Americans with disabilities and their families as we move*

toward 2014?" Participants were given the opportunity to interpret, respond to, and elaborate on the question. NCD used optional follow-up questions for clarification and to account for variations in the depth of understanding, topic significance, and wide-ranging recommendations for collaboration to address specific concerns or problems.

The excerpts compiled from these interviews were not aggregated. They were collected to ensure the diverse voices of the disability community are heard and represented, as anecdotal examples of the most significant, heartfelt, and practical concerns of the community itself, capturing the unique insights, experiences, and expertise of the dedicated individuals with whom NCD conversed.

The review and analysis of these interviews revealed three major characteristics:
- The interdependent nature of some issues impacting people with disabilities makes it difficult to isolate and discuss one issue at a time;
- Deep concerns remain about prospects for withstanding the economic recession, given the unique challenges that the majority of people with disabilities face; and
- The disability rights movement has yet to meet critical and unmet needs.

To organize and address the concerns, observations, and opportunities available for progress, this report presents information under four broad subject areas:
(1) Ratification of the Convention on Rights of Persons with Disabilities (CRPD)
(2) Economic Empowerment;
(3) Health Care and Access to Medical Treatment; and
(4) Community Integration.

Other topics addressed within these primary subject areas include employment, vocational rehabilitation, mental health care, education, housing, transportation, voting, and veteran-specific issues. Where available, data is included to inform and supplement the observations, discussion, and recommendations.

The narrative, data, and recommendations of the 2013 Progress Report are neither exclusive nor comprehensive, but should be viewed as opportunities to identify work yet to be done, in conjunction with NCD's ongoing policy outreach and research, and in collaboration with the Administration, Congress, and other agencies that seek fulfillment of the Americans with Disabilities Act.

NCD will continue to make recommendations and seek partnerships with other branches of government to create and reform federal programs serving Americans with disabilities, and advise the Administration and Congress of its findings.

Although measurable progress has been achieved in many areas, including employment, education, and community living, resulting in an overall state of the disability union that is more robust with increased opportunities and greater accessibility overall, critical challenges remain. In order to make the most of the advances our nation has made, these challenges must remain urgent and be met and overcome with focused attention and prompt and effective action.

INTRODUCTION

Strength in Our Differences is NCD's 2013 Progress Report summarizing the status of federal laws and programs serving an estimated 57 million Americans with disabilities, their families, and the diverse segments of the disability community, in fulfillment of NCD's statutory mandate to annually report and make recommendations concerning the state of disability policy in the United States. Consistent with the tradition begun in NCD's seminal report from 1986, *Toward Independence: An Assessment of Federal Laws and Programs Affecting Persons with Disabilities,* the 2013 Progress Report is derived from the diverse voices of the disability community, including interviews with knowledgeable consumers, advocates, and experts on disability programs, supports, and services from across the nation.

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This report consists of four chapters covering the major issues that Americans with disabilities face toward reaching a goal of full integration and participation in all aspects of life. The concepts of full integration and participation truly have become more achievable goals, since the concept of disability is increasingly understood as an ever-evolving interaction between people with physical, sensory, developmental, or psychological impairments and the attitudinal or environmental barriers that hinder their full and effective participation in society on an equal basis with others.

Chapter 1 leads the report with NCD's strong recommendation that for the United States to maintain its position as a world leader on civil rights, the Convention on the Rights of Persons with Disabilities must be ratified by this nation. Chapter 2 presents the status of

economic empowerment for people with disabilities through a vision of self-determined employment in an integrated workforce with reasonable accommodations, equal pay, and opportunities for advancement, and further supported by access to quality educational opportunities, health care, and asset development. Chapter 3 reviews the current and shifting debate of health care in the United States, especially in light of further implementation of the Patient Protection and Affordable Care Act (ACA), as these initiatives present meaningful opportunities to resolve health disparities and lower or erase barriers to essential health care, wellness, and illness prevention for people with disabilities.

Chapter 4 analyzes the remaining barriers to full participation for people with disabilities in the community, especially education, housing, transportation, voting, home- and community-based long-term services and supports, information and communications technology, and accessible currency. When barriers to civic inclusion are removed and people with disabilities are empowered to participate fully in the community, the entire community benefits. Viewed from this larger perspective, that equal opportunity and greater accessibility benefit society as a whole, NCD closes this report with focused recommendations for the President and Congress to consider and address in the months ahead.

CHAPTER ONE: RATIFICATION OF THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

NCD anticipates that the Senate may again consider ratification of the UN Convention on the Rights of Persons with Disabilities (CRPD) this year. NCD strongly supports ratification because the CRPD offers a vital framework for creating legislation and policies around the world that embrace the human rights and dignity of all people with disabilities.

The CRPD[1] is an international treaty that was inspired by the Americans with Disabilities Act (ADA) in recognizing the rights of people with disabilities across the globe. To date, 156 countries have signed the treaty and 133 have ratified it.[2] President Obama signed the treaty in 2009 and sent it to the Senate for ratification.[3] Support for ratification by the United States comes from all corners of the country, including more than 600 disability organizations, 40 leading faith-based organizations, more than 20 veterans' service organizations, and key leaders from the business community.[4] More than a decade ago, NCD kicked off consideration by the US disability community of an international treaty by publishing a white paper titled "Understanding the Role of an International Convention on the Human Rights of People with Disabilities."[5] Since that time, NCD has been at the forefront, publishing numerous analyses and reports in support of the development, signature, ratification, and implementation of the disability treaty.

Ratification is critical to maintaining our global leadership role and taking the next step in helping eliminate discrimination throughout the world. With more than a decade of careful analysis of the CRPD and related discussions, and 35 years as a trusted expert in disability policy concerns, NCD is ready to provide advice and counsel to the Senate as it deliberates ratification. Once ratified, NCD will proudly work with partners to ensure that the United States has a strong voice in bringing the world closer to a time when all people with and without disabilities are treated equally.

When interviewed for this report, Rep. **Tammy Duckworth**—a former helicopter pilot in the Army who lost both legs and severely and permanently injured her right arm as a

result of injuries received in combat—identified ratification of the CRPD as the most pressing issue for people with disabilities going into 2014. Ratification of the CRPD, said Representative Duckworth,

> *would help guarantee access and protections for disabled persons worldwide— the same protections that Americans earned under ADA in 1990. The Convention on the Rights of Persons with Disabilities will help millions of Americans gain the same rights overseas that they have at home.*

Summary and Recommendation

In light of an increasingly global economy, and proliferating opportunities to travel, work, and live abroad to an unprecedented degree, ratification of the CRPD both reaffirms the nation's commitment to the principles of the ADA at home and extends these protections to Americans and others with disabilities abroad. NCD firmly recommends prompt ratification of the CRPD during the 113th Congress.

CHAPTER TWO: ECONOMIC EMPOWERMENT: EMPLOYMENT AND WORKFORCE PARTICIPATION

Economic empowerment for people with disabilities—as defined similarly for other groups[6]—envisions economic independence arising from self-determined employment in an integrated workforce with reasonable accommodations, equal pay, and opportunities for advancement, and further supported by access to quality educational opportunities, health care, and asset development.[7] This chapter focuses principally on employment and workforce participation. Other contributing factors to economic empowerment are discussed in Chapter 3 "Health Care and Access to Medical Treatment" and Chapter 4 "Community Integration."

> *Employment plays many roles in the lives of individuals; employment provides income and contributes to financial security, it enables individuals to explore and grow their skills and potential, integrated employment supports community living, and, through competitive employment, individuals are taxpayers and may reduce use of public benefits over time. Persistent unemployment creates barriers to reaching these outcomes.*
>
> – **Nanette Relave**, director of the Center for Workers with Disabilities at the American Human Service Association

People with disabilities encounter difficulties, challenges, and barriers that their peers without disabilities rarely experience when seeking employment, job retention, and promotion. Impediments to meaningful employment include concerns by potential employers and coworkers, and the influence of common misconceptions about what a person with a disability is capable of. These challenges also include attitudinal, environmental, and financial aspects of the workplace and often create barriers to self-sufficiency and inclusion.

Hindered by an economy in recession, census data collected by the American Community Survey revealed that in 2011, an estimated 33.1 percent of people with disabilities (ages 18–64) were employed, compared with 73.2 percent of those without disabilities.[8] Employed individuals with disabilities, ages 21–64, earned on average $36,700 per year compared with $42,800 of their peers without disabilities.[9]

Employment numbers for Americans with disabilities have not changed much since passage of the ADA, which was intended to increase civil rights protections for millions of Americans with disabilities and to guarantee their equal opportunity in employment.[10] The 40 percent chasm between the employment rates for Americans with and without disabilities is inarguably disparate and unacceptable. It should come as no surprise that the number one topic on the minds of those that NCD interviewed for the 2013 Progress Report was employment and workforce participation.

As the ADA quarter-century mark nears, continued improvement of the rate of employed Americans with disabilities remains a critical focus.[11] This 40 percent gap is a target for correction through government incentive programs, the elimination of stereotypical assumptions regarding costs and capabilities, and a concerted effort across the nation, in public and private sectors, to ensure full integration of workers with disabilities. This may be achieved with comprehensive, inclusive, and integrated employment, and full and fair opportunities and wages for every segment of American society. For the first time, a brighter future appears possible for American workers with disabilities.

Annually, on behalf of all people with disabilities, the US Department of Labor's (DOL's) Office of Disability Employment Policy (ODEP) selects a National Disability Employment Month theme to reflect that people with disabilities have the desire, education, training, and experience to be successful in the workplace.[12] ODEP's Assistant Secretary Kathy Martinez announced the October 2013 theme as "Because We Are EQUAL to the Task." She also urged "all employers to benefit from the skills of workers with disabilities by giving them, including our returning veterans, a chance to show that they, too, are equal to the task."[13]

This chapter focuses on factors directly impacting employment and workplace participation; that is, a supported inclusive model of employment, workforce investment and the American Job Centers, tax credits and incentives to support people with disabilities in the workforce, federal employment initiatives, disability-owned business

opportunities, attitudinal and workplace barriers, veterans' employment rights, and initiatives of the National Governors Association.

Supported Employment

Supported employment is a model of employment for the broad spectrum of people with physical, sensory, and psychosocial disabilities, and particularly with regard to intellectual and developmental disabilities. It occurs in integrated work settings at equal pay, and receiving natural supports from others in the work environment and/or from a job coach (as needed).[14] A June 2013 article in the journal *Inclusion* provides a concise overview of continuing issues and needs:

> *While supported employment has expanded little in the last decade, there is a renewed investment nationwide and in some other countries. The renewed developments include improvements in supported employment methods, interest in funding based on outcomes rather than services, concern about the persistence of segregated workshops, the need for qualified supported employment personnel, investment in Employment First policies in states, the emergence of litigation promoting integrated employment over segregation, renewed investment in transition, investments in other countries, and the increasingly clear voice of self-advocates with intellectual and developmental disabilities calling for community jobs and fair pay.*[15]

Likewise, the August 2012 NCD report on *Subminimum Wage and Supported Employment* emphasized the need for increased benefits planning, work incentive counseling, peer support, notification of services, infrastructure, education systems change, enforcement, and phasing out of the Fair Labor Standards Act (FLSA) 14(c) subminimum wage program (which permits workers to be paid less than federal minimum wage in certain circumstances).[16]

Approximately 420,000 workers with disabilities are employed under a 14(c) program.[17] Started in 1938 when Congress enacted federal minimum wage legislation,[18] the program permits employers to pay workers less than minimum wage, based on the portion of work a given employee can perform in comparison to a typical employee.[19] The initial intent of the 14(c) program was to employ people with disabilities, who due to

disability could not perform at competitive levels. Over time, these employees were to be trained and demonstrate improvements in performance toward acquiring a greater proportion of the minimum wage, and for the majority to be transitioned into the competitive workforce.[20] Unfortunately, only about 5 percent of all employees with disabilities in 14(c) sheltered workshop programs ever transition out.[21]

Nonetheless, NCD recognizes that "any statement of public policy or recommendation simply to eliminate all Section 14(c) certificates would jeopardize the livelihood and security of many individuals who are currently part of the program."[22] NCD thus recommends a phase-out of the 14(c) program over a period of six years, utilizing personalized employment programs and other outreach that facilitates and provides stability and support to those who have been in the program for a long time, recognition of the fact that it will take time to transition to a supported employment environment.[23]

Many states have resolved to implement "Employment First" policies that promote integrated employment with earnings at or above the minimum wage as the first option of service for individuals with intellectual and developmental disabilities.[24] The state of Washington is a notable example where policy and practice have merged to establish integrated employment as the primary goal for all people with intellectual and developmental disabilities of working age. "In 2009, over 3,000 Washingtonians with developmental disabilities earned over $24 million in wages in integrated, individual community jobs."[25]

In contrast, some parts of the nation have reversed course. On April 1, 2013, the US Department of Justice (DOJ) joined a class-action lawsuit filed against Gov. John Kitzhaber and the state of Oregon, demanding changes to the state's sheltered workshop system.[26] The DOJ stated that 61 percent of Oregon residents with significant disabilities work in sheltered workshops, and that only 16 percent work at businesses with integrated workforces.[27] As recently as the 1990s, Oregon was considered a national leader in providing workplace support. Since then, the number of Oregon residents in sheltered workshops has doubled to approximately 2,600.[28]

Finally, NCD's February 2013 statement on sequestration called attention to several risk factors. The sequester places "tens of thousands of Americans with disabilities at greater risk for hunger and homelessness, endanger[s] the education of millions of children with disabilities and delay[s] employment services and disability benefits for scores of people with disabilities—including disabled veterans—who are, on average, already at greater risk of poverty."[29]

Vocational Rehabilitation

> *While the [perception is the] Americans with Disabilities Act has given us a boost ... In a wider range of employment in the private and public sectors, we still experience barriers—attitudinal, technological, financial, and educational that prevent us from getting jobs that match the training, education and work experience we have. ... We have some employers (or even some fellow employees) that still think we cannot do the jobs we are capable of doing. They choose not to change their mindset to give us the chance to succeed in the workplace or even move up the career ladder as managers or executives.*

> – **Claude Stout,** executive director for TDI (formerly known as Telecommunications for the Deaf and Hard of Hearing, Inc.)

Established and authorized under the Rehabilitation Act, the public vocational rehabilitation (VR) program is the federal-state partnership that funds the primary service delivery system for assisting individuals with disabilities, particularly individuals with the most significant disabilities, to prepare for, obtain, or retain employment. Its focus is "to empower individuals with disabilities to maximize employment, economic self-sufficiency, independence, and inclusion and integration into society."[30]

In 1998, the Rehabilitation Act was incorporated into the broader Workforce Investment Act (WIA) with the expectation that Congress would reauthorize this important legislation every five years. That has not happened despite bills that have been offered in previous Congressional sessions. The 113th Congress is again expected to consider WIA reauthorization with bills in the Senate and House. The Senate bill was developed with

bipartisan support and emphasizes high expectations and competitive integrated employment as the outcome for youth and adults with disabilities, with services to reflect 21st century workforce needs.[31] The proposed provisions also include the establishment of a new Independent Living Administration, separate from the Rehabilitation Services Administration and moved to the Administration on Community Living at the Department of Health and Human Services.[32] As the legislation moves forward, NCD will play a role in assessing the impact of these and other proposed changes.

Each year, about 1 million individuals with disabilities are served by VR.[33] For the first time in many years, fiscal year 2011 data (the most current information available) shows a modest increase (in comparison to the previous year) of 3.7 percent in the number of individuals who achieved a successful employment outcome.[34] NCD recommends that the Rehabilitation Services Administration (RSA) proactively seek stakeholder input and update VR program performance evaluation standards and indicators to reflect 21st century program expectations.

Both professionals with disabilities, **Kevin Irvine** and **Karen Tamley** have a daughter with a disability. They emphasized lost opportunities and the importance of developing and supporting skills to help teens with disabilities transition to adulthood and become part of the workforce. These parents told NCD,

> *There are wasted opportunities with all the thousands of young people in school with identified disabilities; and yet many of them (even if receiving transitional services) leave the educational system without basically having a résumé, or knowing how to create one, without having actual job experience, or an apprenticeship or structured employment or being involved in a job interview or receiving feedback from employers.*

The lingering effects of the economic recession continue to affect many state VR programs. In fiscal year 2012, 16 of the 80 state VR programs relinquished a portion of their federal allotment of funds because they were unable to make the required 21.3 percent state match. A total of $143 million was relinquished.[35] In addition, a total of 22 states and territories did not meet their fiscal year 2011 maintenance of effort

requirement, resulting in $42.6 million in penalty reductions taken from fiscal year 2012 funds.[36] NCD recommends that the Department of Education provide targeted technical assistance to states that continue to return significant portions of their federal allocation each year.

Regardless of the fiscal challenges, youth and adults with disabilities have a right to expect that the VR services they receive prepare them for the 21st century workplace, with the skills to compete in an increasingly global economy and to meet their career aspirations. Various strategies are demonstrating a positive return on investment and provide a sound foundation for further research, collaboration, and innovation.[37]

Using a significant portion of the fiscal year 2012 relinquished VR funds, the Department of Education is partnering with the Social Security Administration and the Departments of Health and Human Services and Labor on the PROMISE initiative.[38] This joint initiative is designed to improve the education and employment outcomes of children receiving Supplemental Security Income program benefits and their families. The Obama Administration has proposed similar uses of the funds in fiscal years 2013 and 2014.[39]

The Wisconsin Vocational Rehabilitation Division is implementing a transition initiative that emphasizes the positive impact of community-based, integrated, paid work at or above minimum wage prior to high school graduation. Wisconsin VR has instituted a statewide Youth On-the-Job Training (Y-OJT) initiative in which VR is providing up to 100 percent of wages for up to 500 hours for high school students that qualify for VR.[40] During federal fiscal year 2012, 1,443 students with disabilities participated in a Y-OJT or paid internship prior to high school graduation. The results tell the story—34 percent of Wisconsin VR's successful employment outcomes for 2012 were for transition-age youth.[41]

The Project SEARCH High School Transition program is a unique, business-led, one-year school-to-work program that takes place entirely at the workplace.[42] Total workplace immersion facilitates a seamless combination of classroom instruction, career

exploration, and hands-on training through workplace rotations.[43] Started at Children's Hospital in Cincinnati, Ohio, Project SEARCH workplace sites can be found in hospitals, county and Federal Government agencies, colleges, and banks.[44] A recent Virginia Commonwealth University research study of Project SEARCH workplace sites shows that intensive internship training, in conjunction with an engaged business such as a hospital, can lead to high levels of competitive employment for youth with autism in areas such as cardiac care, wellness, ambulatory surgery, and pediatric intensive care units.[45]

Since 2009, the Southeast TACE (Technical Assistance and Continuing Education Center)[46] has partnered with state VR agencies in their region to pilot and integrate innovative customized employment (CE) and asset development practices that positively affect employment and self-sufficiency outcomes for people with disabilities.[47] CE has proven to be an effective strategy for providing integrated employment with equal pay for individuals with complex barriers to employment, including significant disabilities.[48] CE begins by using a discovery process to identify the skills, abilities, and interests of the jobseeker and matching them to the unmet business needs of an employer by crafting a unique job designed specifically for the individual.[49]

NCD recommends that the Departments of Education, Labor, and Health and Human Services jointly collaborate on further research and demonstration projects that showcase evidence-based practices such as internships, work experiences, mentoring, and family engagement in ensuring more effective educational and employment outcomes for youth and adults with disabilities.

Workforce Investment and American Job Centers

The US workforce investment system is "an integrated national ... system that supports economic growth and provides workers with the information, advice, job search assistance, supportive services, and training in demand industries and occupations needed to get and keep good jobs. [It] also helps employers acquire skilled workers."[50] The workforce investment system uses approximately 3,000 American Job Centers

(AJCs) funded under the Workforce Investment Act, as well as other public and private entities that provide employment and related services to jobseekers with and without disabilities.[51]

The AJCs (previously known as Career One-Stop centers) provide jobseekers of all skill and experience levels access to a comprehensive range of services and tools in a single convenient location. Services commonly include career counseling and planning, education and training referrals, training on résumé building, job search strategies, interviewing skills and computer basics, job search assistance, connections to hiring employers, direct job placement, information about the labor market and unemployment compensation, and access to telephones, fax machines, computers, and copiers.[52]

Extending the reach of the workforce investment system, ODEP is working to increase successful, integrated employment outcomes and financial stability for people with disabilities through new capacity-building and employment initiatives throughout the system. Both previous and current ODEP initiatives demonstrate that with capacity-building, training, and technical assistance, AJCs can serve a broad range of individuals with significant barriers to employment, including a disability.[53]

For instance, ODEP's National Center on Leadership for the Employment and Advancement of People with Disabilities (LEAD)[54] is working with many AJCs across the nation to implement a recently developed process of group discovery for jobseekers with and without disabilities and other barriers to employment.[55] Group discovery allows AJCs to move individuals through the process in small groups rather than individually. The group discovery process can result in either wage or self-employment, which allows for more flexibility and increased productivity in deciding when and how work is performed in order to accommodate the needs of jobseekers with disabilities and to maximize potential placements.[56] Group discovery further benefits AJCs by using staff time more efficiently.

The LEAD Center also provides technical assistance to the AJCs on developing, promoting, and bringing to a national scale evidenced-based policies and innovative practices to improve service delivery. The policies and practices include CE, self-employment, the use of workplace flexibility,[57] and other strategies.[58] Utilization of these and other interventions within the AJCs bolsters opportunities for youth and adults with disabilities to find and retain jobs.

ODEP is also using AJCs to implement the Customized Employment Demonstration Initiative.[59] These initiatives have shown that to fully meet the needs of jobseekers with disabilities, it is important for AJCs to partner with other agencies (both general as well as disability-specific) that provide employment-related services. Partnering better facilitates changes in the way decisions are made by leveraging policies and linking funding and services to facilitate improved collaboration.[60] By coordinating resources and funding of partner agencies, an AJC can expand its menu of services to respond to the employment needs of jobseekers with disabilities in an individualized and comprehensive manner.

Building on these initiatives, ODEP and DOL's Employment and Training Administration (ETA) jointly fund the Disability Employment Initiative (DEI) for the purpose of "improv[ing] educational, training and employment outcomes of youth and adults with disabilities who are unemployed, underemployed and/or receiving Social Security disability benefits."[61] Through DEI, these agencies have awarded grants to 23 states to validate effective practices identified in previous DOL initiatives.[62]

Among the practices being validated through the DEI are partnerships and collaborations between state agencies to coordinate policies and funding streams to support innovative AJC practices, self-employment supports, CE, and the youth-focused *Guideposts for Success*.[63] DEI has created the *Promising Practices* series containing "videos and information briefs ... [that] promote positive employment outcomes of people with disabilities."[64] Topics address at-risk youth, subsidized employment opportunities for low-income parents, re-employment strategies for current and former welfare recipients, and

moving people with disabilities into state government careers, among other things.[65] NCD recommends funded implementation of validated, successful DEI strategies, and funding for the validation of additional DEI strategies such as for partnerships and collaborations between state agencies, self-employment supports, customized employment, re-employment strategies, and moving people with disabilities into state government careers.

On March 18, 2013, ODEP released its training and employment notice to announce the availability of "What's My Next Move?"—a guide to exploring careers online using electronic tools from the DOL.[66] The guide supports high school students in developing their education and career plans by walking them through seven steps of career inquiry.[67] The toolkit information includes self-paced courses and resources for seeking additional help in workplace preparation.[68] A corollary source is the "My Next Move" portal at http://www.mynextmove.org/.

Amid these many initiatives, it is not evident that the workforce investment system has included benefits planning services for workers with disabilities and others who must carefully balance federal and state benefits with income or risk losing important supports such as Medicaid and personal assistance services.[69] Chacku Mathai, Associate Executive Director of New York Association of Psychiatric Rehabilitation Services, emphasized that:

> *[. . . the AJCs] should also include benefits advisement so that people can find out more information about how much they can earn to retain benefits.*

The New York Makes Work Pay (NYMWP) project explains that "Benefits and Work Incentives Planning and Assistance [WIPA] is a critical employment support for individuals with disabilities who receive public entitlements."[70] NYMWP established seven WIPA programs in New York equipped to "provide work incentives planning and assistance; help beneficiaries and their families determine eligibility for Federal or State work incentives programs; refer beneficiaries with disabilities to appropriate Employment Networks or State VR agencies based on individual needs and impairment types;

provide general information about potential employer-based or federally subsidized health benefits coverage available to beneficiaries once they enter the workforce; and inform beneficiaries with disabilities of further protection and advocacy services available to them."[71]

NYMWP provides additional resources on "Self-Employment and the Benefits Planning Process"[72] and "developed a Work Incentives Information Network to increase the number of certified benefits and work incentives specialists available statewide."[73] NCD recommends the inclusion of benefits planning as a component of the American Job Centers.

Tax Credits and Incentives

Current provisions in the federal tax code are available to support and incentivize employment for people with disabilities. These include: Household and Dependent Care tax credit, Impairment-related Work Expenses (IRWEs) tax deduction, Flexible Spending Arrangement (FSA) tax exclusion, and Dependent Care Assistance Program (DCAP) for workers with disabilities or with family members who have disabilities. The Disabled Access Credit was designed to encourage employers to hire workers with disabilities. This section examines Work Opportunity Tax Credit, American Taxpayer Relief Act of 2012, and Expanded Tax Credit for Hiring Unemployed Veterans[74] as well as state-specific provisions.

Household and Dependent Care is a "tax credit to assist household taxpayer to engage in gainful work while affording necessary care for a dependent. The credit is available for costs incurred to care for a family member so that another family member may work."[75] An IRWE is an "itemized tax deduction for workers with disabilities and family members, who incur disability-related costs in order to work. It covers attendant care services at the individual's place of employment and other expenses in connection with employment."[76] An FSA is an "exclusion from taxable income of medical expenses not covered by employer's insurance plan. The employee sets aside a predetermined amount from

paycheck, which the employer uses to pay the employee's non-covered costs."[77] The DCAP is an "exclusion from taxable income of up to $5,000 of qualifying costs for dependent care assistance" under an employer-elected DCAP that is made "available to employees with dependents who have disabilities."[78]

The Disabled Access Credit will "reimburse accommodation costs paid by small businesses that employ workers with disabilities and/or serve customers with disabilities. Costs include purchase and use of communication assistance and accommodations such as a Braille printer, voice recognition software, or large print emergency exit signage."[79] Though a significantly underutilized provision,[80] the Disabled Access Credit can be a valuable asset to small and medium-sized businesses in increasing employment opportunities for people with disabilities.

The Work Opportunity Tax Credit promotes the hiring of people who qualify as having barriers to employment, including veterans, VR referrals, and recipients of Temporary Assistance to Needy Families, the Supplemental Nutrition Assistance Program, and Supplemental Security Income.[81] The American Taxpayer Relief Act of 2012 and the Expanded Tax Credit for Hiring Unemployed Veterans also positively affect the disability community.[82] The expansion of tax credits to taxpaying employers and nonprofit organizations that hire veterans with service-connected disabilities acquired before January 2014 is a viable example of the commitment of the Obama Administration to American veterans, including those with disabilities.[83]

Tax incentives are also available on the state level. The New York State Department of Labor's Economic Development Services offers the "Workers with Disabilities Tax Credit," providing employers $2,100 for every person with a disability they hire.[84] The Pennsylvania Department of Labor and Industry and the Department of Community and Economic Development provide grants to small businesses with 100 employees or fewer through the ICAN Fund administered by the state VR. The ICAN Fund provides grants of up to 80 percent of the total cost (up to $40,000) for small businesses to make workplace

accommodations and site modifications, provide specialized or adapted machinery, or provide specialized training for employees with disabilities.[85]

NCD recognizes there remain significant federal financial disincentives to employment impacting the disability community, often arising from competing purposes within federal statutes and agencies.[86] In the August 2008 report, *The State of 21st Century Financial Incentives for Americans with Disabilities*, NCD explained, "No single agency or policy solution can produce the comprehensive reforms needed to align financial incentives that directly and indirectly will support the range of choices people with disabilities desire to be fully productive, independent, and active participants in the economic mainstream."[87]

In 2008, NCD called for collaborative actions involving the Administration, Congress, and interagency partners to eliminate financial barriers and align financial incentives that support employment for greater numbers of people with disabilities.[88] NCD again recommends that the President "create a federal interagency workgroup[89] on financial incentives for people with disabilities and their families; develop an Executive [O]rder calling for all agencies to identify policy barriers; and create a time-limited body to facilitate a consistent, coordinated, comprehensive, and consumer-friendly approach to advance opportunities for full community participation and economic self-sufficiency."[90]

NCD further recommends that the federal interagency workgroup specify outcome-based tasks for each participating entity, which include developing a national awareness and technical assistance outreach campaign to raise public awareness of tax provisions that support employment opportunities for Americans with disabilities. NCD further recommends that the Internal Revenue Service report annually to the federal interagency workgroup on the number of individuals and businesses utilizing tax provisions that support employment opportunities for Americans with disabilities, the amount of tax credits and deductions claimed, and the numbers of workers that benefit.

Federal Employment / Executive Order 13548

In July 2010, President Obama issued Executive Order 13548 with the goal of hiring 100,000 people with disabilities in the federal workforce by 2015 and holding federal agencies accountable for their progress.[91] In addition to re-establishing the goal originally set during the Clinton Administration, the Executive Order created specific deadlines and requirements of federal agencies to recruit, hire, train, and retain workers with disabilities.[92] In fiscal year 2011, "people with disabilities composed 14.7 percent of newly hired, full-time, permanent federal employees. Almost 19,000 newly hired federal employees had a disability, reversing the long-term trend of a shrinking federal workforce with disabilities."[93] As of 2012, 11 percent of all federal employees identify as having disabilities.[94]

On March 25, 2013, the Office of Personnel Management (OPM) published new final regulations to streamline the federal employment process for people with disabilities.[95] Federal civilian jobs are part of the competitive civil service workforce; however, OPM provides hiring authority to fast-track the filling of jobs in special or unusual circumstances.[96] Under Schedule A, one of four such exceptions, the new regulations clarify that for temporary appointments, people with intellectual disabilities, severe physical disabilities, and psychiatric disabilities who apply for "excepted" federal jobs can be appointed without the burden of providing a third-party certification of readiness for temporary appointment.[97] OPM explained that now "agencies have the option of giving individuals with disabilities, who do not have work, educational, or other relevant experience, a temporary appointment that will allow them to establish their job readiness."[98] Schedule A also permits hiring without posting and publicizing the position.[99]

These federal employment initiatives are positive trends that serve as an important model for state and local governments and all kinds and sizes of businesses across the nation.[100]

Disability-Owned Businesses

Entrepreneurs with disabilities have more opportunities in 2013 than ever before for self-employment. Federal and state programs are increasing in number and reach to incentivize doing business with disability-owned businesses. Disability-owned businesses are well positioned to bid on federal contracts. Section 503 of the Rehabilitation Act of 1973 requires employers with federal contracts or subcontracts that exceed $10,000 to take affirmative action to hire, retain, and promote qualified individuals with disabilities.[101] NCD supports modernization of the Section 503 regulations including the proposed 7 percent utilization goal for employment of individuals with disabilities as a benchmark for each job group in a federal contractor's workforce.[102]

The Small Business Administration (SBA; a federal agency) promotes business ownership for people with disabilities as a means of creating work flexibility and financial stability. Though not directly involved in assisting people with disabilities to start or finance a small business, SBA has developed a list of resources on these topics and others. See: http://www.sba.gov/content/people-with-disabilities.

State initiatives in support of disability-owned businesses are becoming more common. The Mississippi Capital Access Contract Loan Program "assists socially and economically disadvantaged businesses as designated by the U.S. Small Business Act by providing loans to borrowers with contracts with public entities who, for various reasons, might have difficulty in obtaining conventional loans."[103] Also, the Illinois Minority, Women, and Disabled Participation Loan Program for Minority / Women / Disabled / Veteran-Owned Businesses category is "designed to enable small businesses to obtain medium to long-term financing … in the form of term loans, to help them grow and expand their businesses."[104]

A highly successful alternative program facilitating small business ownership by veterans with disabilities is the Entrepreneurship Bootcamp for Veterans with Disabilities (EBV).

EBV began at the Whitman School of Management at Syracuse University in 2007. Since then, EBV has been expanded to seven other national business and management schools. EBV "offers cutting edge, experiential training in entrepreneurship and small business management to post-9/11 veterans with service-connected disabilities."[105] EBV has graduated 618 veterans with disabilities since 2007.[106] Among the training outcomes for these veterans, 16 percent are in the business planning stage, 65 percent have a current business venture in operation, 13 percent returned to school, and 5 percent are employed by someone else.[107] Further, 91 percent of graduates use the EBV-TAP (technical assistance program), which provides ongoing, free access to experienced business mentors.

During NCD's January 2013 quarterly meeting, Jill Houghton, executive director of the US Business Leadership Network (USBLN) confirmed that business-to-business networking is alive and well: "promoting disability inclusion in the workplace, in the marketplace, and in the supply chain."[108] Prompted by inquiries from IBM and Wal-Mart, the USBLN set out to create a disability-owned business certification on par with those for businesses owned by women, veterans, and people of diverse racial/ethnic backgrounds. Ms. Houghton explained:

> *Back in 2008, two corporations, IBM and Wal-Mart, came to the USBLN and they asked us why there wasn't an entity out there that was certifying businesses as being 51 percent owned, operated, controlled, and managed by a person or people with disabilities. And the reason why they asked … was because they were thinking seriously about beginning to include doing business with disability-owned businesses in what's called their supplier diversity program. It wasn't something that the government said they had to do. It's something that they believed made good business sense.[109]*

In 2013, the USBLN has certified the first 40 disability-owned businesses, ranging in size and revenue from 1 to 80 employees and from $10,000 to $580 million, respectively. Presently, the USBLN has recruited 30 corporations including Ernst & Young, Walgreens, and OfficeMax, who recognize this certification and are doing business with disability-owned businesses.[110]

NCD recommends that stakeholder dialogue focus on strategies for federal and state governments to implement preferred contractor programs for disability-owned businesses. The existing federal set-aside contracts using designated diversity factors (e.g., gender, race/ethnicity, veteran status) for identifying business ownership should be expanded specifically to include disability-owned business. NCD stands ready to engage as a facilitator with the US Business Leadership Network and federal partners starting with the Departments of Labor, Commerce, Health and Human Services, and Education and the Small Business Administration.

Attitudinal and Practice Barriers and Facilitators to Meaningful Employment

Among the greatest barriers to workplace success are unfavorable attitudes toward the employment of people with disabilities.[111] Barriers may be linked to job applicants as well as potential employers. "A common and not unfounded fear that continues to be widespread is that disclosing a disability may lead to not being selected for a position or result in differential treatment in the workplace. Concerns also include lowered expectations, lack of respect, isolation from co-workers, decrease in job responsibility, and being passed over for promotion."[112]

Claude Stout, executive director for TDI (formally known as Telecommunications for the Deaf and Hard of Hearing, Inc.) expressed that unexamined attitudes and stereotypical assumptions are key barriers to employment. Just as innovative ideas can expand opportunities for aspiring workers without disabilities, a lack of understanding is often the most deciding factor in holding people back:

> *While the [perception is the] Americans with Disabilities Act has given us a boost ... in a wider range of employment in the private and public sectors, we still experience barriers—attitudinal, technological, financial and educational that prevent us from getting jobs that match the training, education and work experience we have. ... We have some employers (or even some fellow employees) that still think we cannot do the jobs we are capable of doing. They choose not to change their mindset to give us the chance to succeed in the workplace or even move up the career ladder as managers or executives.*

Michael Zelly, president of the Disability Network in Flint, Michigan, links a shift in attitude to a shift in results:

> *Educating employers of the benefits of hiring persons with disabilities is important. Businesses need to discover that most people who are disabled are so thankful to be working that they work very hard and it rubs off on the other employees. Walgreens South Carolina distribution center of 600 employees has 40 percent workers with disabilities. Businesses need to align with state vocational rehabilitation agencies that have high expectations for their clients. VR agencies could collaborate with businesses like Walgreens in raising awareness of the benefits of hiring workers with disabilities.*

Findings and recommendations from the Interagency Committee on Disability Research for changing employer and workplace attitudes include (1) exploring how the dynamics of corporate culture (espoused policies, everyday practices, and supervisor and coworker attitudes) influence the hiring, integration, and career advancement of people with disabilities;[113] (2) encouraging disability awareness and ADA and job accommodations training to improve managers' attitudes toward people with disabilities; and (3) focusing on interventions at the senior management level that change company policies to include disability as part of the company's diversity efforts.[114]

Efforts to promote an inclusive workplace culture may have a long-term impact on employer hiring and retention practices that positively impact people with disabilities. Corporate culture research using large data sets acquired through surveys among Fortune 500 companies has made several key findings.[115]

> *When workers with disabilities experience the benefits of an inclusive culture, they are likely to be more satisfied with the job, and often [are] correspondingly more loyal and invested in the work product and performance. In addition, a disability-inclusive culture often will provide positive results for overall employee satisfaction and productivity among workers with and without disabilities. This occurs because when an organization commits to equity, flexibility, and professional development for workers with disabilities, it frequently will generate more employer responsiveness to the individual capacities, health needs, or varying work preferences of employees who may not identify as people with disabilities. In other words, inclusive cultures promote healthy and functional organizational environments.[116]*

Additionally, "the quality of the relationship between management and employees with disability has been identified as a critical factor in developing an inclusive workplace culture."[117] Providing inclusive culture training for middle managers "is a critical means to draw attention to and debunk stereotypical assumptions about the capabilities, independence, and skill sets of people with disabilities."[118] Moreover, an understanding of the role for inclusive workplace practices, and the resources available to implement them, can have a real impact on the cost of doing business. For further resources on implementing an inclusive workplace, see http://bbi.syr.edu/projects/Demand_Side_Models/Toolkit.html.

NCD recommends that by March 3, 2014, the Departments of Labor, Commerce, and Education, and the Small Business Administration initiate dialogue with higher education and disability stakeholders, including the Association to Advance Collegiate Schools of Business and the Association of Higher Education and Disability, regarding the implementation of inclusive corporate culture coursework in business and management schools. Existing examples of inclusive corporate culture might serve as models for consideration during discussions.[119] The intent is to equip the next generation of business leaders, employers, and managers with essential knowledge and skills for creating inclusive workplaces that hire, accommodate, pay, and promote individuals with disabilities at rates comparable to other traditionally underrepresented groups in the workforce.

Andrew Phillips, policy attorney for the National Association of the Deaf, suggested that in order to remove barriers to employment and implement expanded use of appropriate accommodations, certain economic disincentives need to be removed. Although centralized funding in the workplace has not gained consensus, this approach is being advocated in a variety of circles:

> *The National Association of the Deaf recommends that businesses and governments centralize all funding of accommodations for employees with disabilities. When managers have to pay for the cost of accommodations out of*

their division budget there is a disincentive to hiring people with disabilities and especially those who need ongoing accommodations. When the accommodation funds are centralized and not a part of the division budget, managers and hiring officials are more likely to hire a person with a disability since there would be no economic disincentive within the division.

In a July 2012 Senate Committee on Health, Education, Labor, and Pensions report, the committee chair, Senator Tom Harkin, recalls positive responses to change by private employers and governors: "In April 2011, at a disability employment summit hosted by the US Chamber of Commerce and the US Business Leadership Network, I challenged the employer representatives in the room to work to increase the size of the disability workforce from under five million to six million by 2015. This goal was quickly endorsed by the US Chamber of Commerce. This private business endorsement in partnership with the President's initiatives is the type of collaboration we need to move the needle on disability employment. Governors also have an important role to play in elevating this issue, which affects every state budget and every state's economy."[120]

In April 2013, the National Governors Association (NGA), a bipartisan organization composed of the governors of the 55 states, US territories, and commonwealths—which promotes state leadership, shares best practices, and seeks to speak with a collective voice on national policy—made a commitment to the employment of people with disabilities.[121] Delaware Gov. Jack Markell announced that the NGA will focus attention on boosting disability employment as a signature initiative for the duration of his chairmanship of the organization. During his one-year term as chair, Governor Markell promised to create a "blueprint for businesses and states that identifies best practices and outlines steps that can be put in place to increase economic opportunity and heighten awareness. It will provide governors and state policymakers with more policy options to assess the environment in their state and specific strategies designed to support this population. It doesn't matter whether someone was born with additional challenges to face or—in the case of our wounded veterans, for example—acquired them later in life. There are so many people with disabilities who have the time, talent and desire to make meaningful contributions to interested employers. What matters is

what they have to offer and the tremendous impact this will have on their overall well-being and on the bottom line of the businesses that employ them."

Veterans Employment

Federal law provides important protections for veterans with disabilities who are looking for jobs or are in the workplace. ADA Title I and the Uniformed Services Employment and Reemployment Rights Act (USERRA) protect veterans from employment discrimination. Title I, which is enforced by the US Equal Employment Opportunity Commission (EEOC), prohibits private and state and local government employers with 15 or more employees from discriminating against individuals on the basis of disability.[122] Under USERRA, service members who leave their civilian jobs for military service are permitted to perform their duties with the knowledge that they will be able to return to their jobs with the same pay, benefits, and status they would have attained had they not been away on duty. USERRA also prohibits employers from discriminating against these individuals in employment because of their military service.[123]

Ron Drach, president of Drach Consulting and founding board member of Wounded Warrior Project, stressed the importance of vocational rehabilitation and training for veterans with disabilities:

> *Employment continues to be my primary concern for [people with disabilities] and wounded warriors and disabled veterans. We need a strong National employment policy that is all inclusive and avoids tokenism. ODEP is doing a great job in leading this effort. As part of that larger concern is the issue of training for careers that are in the civilian labor force and not provide training for non-existent jobs or skill sets that might be nice to have but don't lead to employment. We need a robust vocational rehabilitation program at the state and Veterans Affairs level. There is a critical skills shortage that contributes significantly to high unemployment and drop out of the labor force among PWD and wounded warriors.*

The unemployment rate for all veterans "ages 18 and over in the civilian labor force"[124] is 6.3 percent compared with 7.5 percent for nonveterans in the same group.[125] However, the current unemployment rate of veterans of the wars in Afghanistan and Iraq is 7.2

percent, compared with 4.9 percent for veterans of the first Gulf War. A slightly greater proportion of veterans of the first Gulf War (81.4 percent) are working or seeking a job, than veterans of the wars in Afghanistan and Iraq (79.7 percent).[126]

Edwin J. Salau, a health services integrator in North Carolina and a veteran working with former service members, told NCD about the effects of stigma and attitudes on the employment of veterans:

> *The most important issue is the hiring barrier facing combat veterans ("disabled" or otherwise), especially those who have multiple tours of duty. Hiring managers and HR professionals fear hiring veterans because of the stigma associated with psychiatric and neurotic diagnoses (whether real or perceived). Subjective evidence is prevalent in Google searches and casual browsing of all news media. This is an insurmountable barrier because job applicants are seldom able to prove discrimination in these situations. This is the single most important public policy issue for Americans because the rejection resulting from such actions, coupled to the expected deterioration of the applicants' optimism and self-worth, creates a generation of dependent, unemployed citizens who become perpetually disabled instead of gainfully employed and productive. Tie this "doom and gloom" scenario to the families directly involved, and it(s) not hard to see the impact on communities, nationwide.*

Another concern for veterans is that although military pay is exempt under sequestration, cuts to other programs and services affecting the employment of veterans, including those with disabilities, place military families at risk. Programs such as TRICARE,[127] tuition assistance, and family support are not exempt and do fall under sequestration.[128]

In support of working veterans and veteran spouses, NCD recommends that Congress enact a budget or bill to restore funding to the Army Community Service, Fleet and Family Support Centers, Airman and Family Service Centers, Marine Corps Community Services, Child Development Centers, and Child and Youth Services in order for them to provide counseling, financial advice, new parent support programs, survivor outreach, and victim advocate services.

Rory Cooper, distinguished professor of the Department of Rehabilitation Science and Technology, School of Health and Rehabilitation Sciences, University of Pittsburgh, illustrates a comprehensive approach to finding solutions to improve outcomes for all people with disabilities:

> *Without employment people with disabilities will continue to have limited voice in government, the economy, and in their communities. Further, employment provides economic freedom which leads to far greater autonomy. ... This is a complex problem, but progress can be made. State vocational rehabilitation agencies need to be more focused on helping people with disabilities gain and retain employment. Rehabilitation counselors need to be better trained in assistive technology to promote employment. State and Federal governments need to hire more people with disabilities, and require government contractors to hire [people] with disabilities. The Department of Justice needs to be more aggressive about ADA compliance in the workplace. Programs are needed to help people with disabilities learn jobs skills and successful workplace behavior. More grants are needed to fund college, especially in STEM fields. Public sector has to hire people with disabilities and promote them. There should be real incentives to do so. Government needs to identify and publicize successful people with disabilities who are working and their employers such as ODEP is doing. More research is needed to identify barriers and facilitators to employment.*

Summary and Recommendations

As emphasized by the interviews conducted for this Progress Report, employment is the key to lifting millions out of poverty, and achieving fulfillment, independence, and success for Americans with disabilities who desire to be part of the American dream.[129] Among the benefits to Americans with disabilities, their families, and the nation are full and fair employment opportunities and advancement, clear participation in the marketplace as contributing workers and consumers, enriched education, life comforts, civic participation, and full integration into the fabric of American society.

Despite significant progress in several areas, including a move away from segregated employment and an increase in federal hiring, numerous barriers continue to limit full inclusion and participation of most Americans with disabilities in the workforce. NCD makes the following recommendations.

- **2.1** NCD recommends that the Department of Labor begin a phase-out the FLSA 14(c) program over a period of six years, using personalized employment programs and other outreach that facilitates and provides stability and support to those who are or have been in the program for a long time and who will need time to transition to a supported employment environment.

- **2.2** NCD recommends that RSA proactively seek stakeholder input and update VR program performance evaluation standards and indicators to reflect 21st century program expectations by December 31, 2015. Specifically, NCD recommends increasing the federally required minimum expectation related to the successful rehabilitation rate (reflecting the rate of successful employment plans completed, compared with the rate of employment plans initiated) from 55.8 percent to 80 percent.

- **2.3** NCD recommends that the Department of Education provide targeted technical assistance to those states that continue to return significant portions of their federal VR allocation each year.

- **2.4** NCD recommends that the Departments of Education, Labor, and Health and Human Services jointly collaborate on further research and demonstration projects that showcase evidence-based practices such as internships, work experiences, mentoring, and family engagement in ensuring more effective education, transition, and employment outcomes for youth and adults with disabilities.

- **2.5** NCD recommends the Department of Labor fund implementation of validated, successful Disability Employment Initiative strategies, and fund the validation of additional DEI strategies such as partnerships and collaborations between state agencies, self-employment supports, customized employment, re-employment strategies, and moving people with disabilities into state government careers.

- **2.6** NCD recommends the inclusion of benefits planning as a component of the American Job Centers.

- **2.7** NCD recommends that by January 1, 2014, the President create a federal interagency workgroup on financial incentives for people with disabilities and their families; develop an Executive Order calling for all agencies to identify policy

- **2.8** NCD recommends that the federal interagency workgroup specify outcome-based tasks for each participating entity, which include developing a national awareness and technical assistance outreach campaign to raise public awareness of tax provisions that support employment opportunities for Americans with disabilities.

- **2.9** NCD recommends that the Internal Revenue Service report annually to the federal interagency workgroup on the number of individuals and businesses utilizing tax provisions that support employment opportunities for Americans with disabilities, the amount of tax credits and deductions claimed, and the numbers of workers that benefit.

- **2.10** NCD recommends that stakeholder dialogue focus on strategies for federal and state governments to implement preferred contractor programs for disability-owned businesses. The existing federal set-aside contracts using designated diversity factors (e.g., gender, race/ethnicity, veteran status) for identifying business ownership should be expanded specifically to include disability-owned business. NCD stands ready to engage as a facilitator with the US Business Leadership Network and federal partners starting with the Departments of Labor, Commerce, Health and Human Services, and Education and the Small Business Administration.

- **2.11** NCD recommends that by March 3, 2014, the Departments of Labor, Commerce, and Education, and the Small Business Administration initiate dialogue with higher education and disability stakeholders, including the Association to Advance Collegiate Schools of Business and the Association of Higher Education and Disability, regarding the implementation of inclusive corporate culture coursework in business and management schools.

- **2.12** In support of working veterans and veteran spouses, NCD recommends that Congress enact a budget or bill to restore funding by June 30, 2014, to the Army Community Service, Fleet and Family Support Centers, Airman and Family

Service Centers, Marine Corps Community Services, Child Development Centers, and Child and Youth Services in order for them to provide counseling, financial advice, new parent support programs, survivor outreach, and victim advocate services.

CHAPTER THREE: HEALTH CARE AND ACCESS TO MEDICAL TREATMENT

People with disabilities experience both health disparities and specific problems in gaining access to appropriate health care, including wellness and illness prevention programs and services.[130] Compared with peers without disabilities, Americans with disabilities frequently lack either health insurance or coverage for essential services like specialty care, long-term care, services coordination, prescription medications, durable medical equipment, and assistive technologies.[131] People with disabilities therefore tend to be in poorer health and use health care at a significantly higher rate than those without disabilities.[132] They also experience a higher prevalence of secondary conditions and use preventive services at a lower rate than those without disabilities.[133]

People with disabilities are affected disproportionately by barriers to services that prevent them from accessing appropriate, timely, preventative, and affordable health care. These barriers include employer practices,[134] health care provider stereotypes about disability, lack of appropriate health provider training, lack of access to medical care and information,[135] lack of accessible medical facilities and examination equipment, and lack of access to sign language interpretation and other crucial individualized accommodations.[136]

For instance, people with disabilities often question whether their potential employer will offer an insurance package that meets their needs. **Betsy Barkley Valnes**, independent contractor and executive director of the National Youth Leadership Network, offered this perspective:

> *More and more employers are offering positions just under the number of hours in which a benefits package would be provided, part-time positions rather than full-time or contract positions with no benefits included, for example. While limitations such as these, in part, may be related to budget shortfalls, the number of jobs that people with disabilities would be inclined to apply for because of the dependence on coverage would be limited nonetheless.*

Furthermore, people with hidden disabilities often experience additional barriers to health care arising from public stigma toward their conditions, including those with mental health and chemical sensitivity impairments.[137]

Mary Lamielle, executive director of the National Center for Environmental Health Strategies, who has worked for over three decades to protect public health and improve the lives of people who have been affected by chemical and environmental exposures, explained the attitudes that create barriers and hinder implementation of more inclusive policies:

> *People with chemical and electrical sensitivities are frequently not treated with respect. They are not understood. … They frequently face discrimination whether at work, at school, in the community, in their families. They are mocked, ridiculed and face active and subtle harassment every day that keeps them from conducting anything that might be considered a "normal" lifestyle. People with these hidden disabilities have reported hostility or discrimination from being intentionally exposed to pesticides, perfumes, air fresheners, or deodorizers; to being taunted by neighbors, coworkers or family members—you mean we can't spray a pesticide here?*

Additionally, federal health care funding agencies such as the Centers for Medicare & Medicaid Services (CMS) neither conduct oversight of ADA architectural and programmatic accessibility compliance by states, health plans, and medical providers, nor assess health providers' disability cultural competence. Few professional health care training programs have disability as part of their curricula, and most federally funded health disparity research does not recognize or include people with disabilities as a distinct population.[138] For instance, **Teresa Pichardo**, a member of the National Youth Leadership Network's Volunteer Team and a person who is deaf, explains:

> *Doctors and hospitals need to have a better understanding and incentive to provide interpreters for deaf and hearing impaired people at medical appointments.*

These challenges affect overall quality of life, productivity and well-being of greater numbers of Americans as the general population ages, and veterans with disabilities

returning to civilian life—logically increasing the number of people with disabilities.[139] Given these challenges, it is especially important to understand the complex and interrelated factors that contribute to health and health care inequities for people with disabilities, and to identify practical solutions.

Kathleen Downes, a University of Illinois Community Health student at the California Foundation for Independent Living, expressed the need for greater awareness among the general population of the health care needs of people with disabilities.

> *Disabled people have been vocal about healthcare concerns especially during the election season and that's a good beginning, but we sometimes forget that the non-disabled population needs to be better educated about how healthcare legislation affects us all. The exclusion of personal care services from coverage threatens independent and community living options. Anyone could become disabled themselves at any time and we need to plan for it now. The notion that "this doesn't concern me" is an illusion that no one can afford, personally or socially. Short term solutions that haven't been properly thought through can cause serious—maybe irreversible long term damage. It is better to avoid a problem than to repair something later.*

This chapter reviews the status of health care services for people with disabilities, as the nation enters into a new era of care under the Patient Protection and Affordable Care Act and increasing Medicaid managed care. Analysis of services and challenges in providing mental health care and health care for veterans are areas of separate attention.

Patient Protection and Affordable Care Act

In the March 19–20, 2013, newsletter from the Department of Health and Human Services (HHS), Secretary Kathleen Sebelius wrote: "Enacted three years ago, the health care law is making the insurance market work better for you by prohibiting some of the worst insurance industry practices that have kept affordable health coverage out of reach for millions of Americans."[140]

Starting in 2014, the ACA guarantees that all Americans (regardless of their health status or preexisting conditions) finally will have access to quality, affordable health care

coverage. Open enrollment to choose among a selection of these health plans begins on October 1, 2013, and coverage begins January 1, 2014.[141] Nonetheless, many people with disabilities are confused or have concerns about the changes to public and private health care. **Amy Doherty**, currently serving as the president of the National Youth Leadership Network Governing Board, expressed the kinds of concerns many people share about health care reform:

> *People with disabilities need to be involved in the transformation discussions that affect their lives, but it is difficult to understand all the ins and outs of healthcare reform. It is complicated and has not been explained clearly enough. There are so many agencies involved, state and federal regulations, qualifications and requirements to digest. People are expected to understand the changes but many lack opportunities for access to resources to learn more.*

Few resources for understanding the complexity of the new health care provisions are simple. The Kaiser Family Foundation provides a useful and balanced overview of the changes with their seven-minute, close-captioned video, "The YouToons Get Ready for Obamacare: Health Insurance Changes Coming Your Way Under the Affordable Care Act" (see http://kff.org/health-reform/video/youtoons-obamacare-video/).

The ACA promises new benefits and improved health care services that will have a direct impact on the disability community. These include the lifting of lifetime caps, elimination of preexisting condition exclusions, preventative care for seniors, punitive actions against hospitals for "rebounding" senior admissions, more people covered by Medicaid managed care, and additional services for people with mental health conditions.[142]

Beginning January 1, 2014, the ACA requires all individual plans (for those who are not eligible for a group plan or public program), small group plans (businesses with up to 50 or 100 employees, varies by states),[143] and large employer plans (more than 50)[144] to limit consumers' out-of-pocket costs and provide a set of essential benefits.[145] The ACA defines "employee" for the purpose of determining employer requirement, as any full-time equivalent (130 hours/month) employee.[146] Essential benefits include ambulatory

patient services (e.g., doctor's visits, outpatient services), emergency services, hospitalization, maternity and newborn care, mental health and substance use disorder services (including behavioral health treatment, prescription drugs, rehabilitative and habilitative services and devices), laboratory services, preventive and wellness services and chronic disease management, pediatric services, and oral and vision care.[147] The essential benefits guarantee a minimum of services that also specifically benefit all people with disabilities to not delay seeking treatment and to proactively avoid unnecessary exacerbations of conditions.

Further, all plans are prohibited from imposing lifetime or annual benefit limits, and must cover adult children until age 26.[148] All plans except self-insured plans "must provide rebates to consumers if the percentage of premiums spent on medical services falls below 85 percent for large group plans or 80 percent for small group and individual plans. …"[149] All plans, except those grandfathered in, are prohibited from having copayments and deductibles for some preventive services, "from requiring a referral to see an OB-GYN and from requiring prior authorization or higher cost sharing for out-of-network emergency services."[150] Out-of-pocket expenses must be limited to $6,400 (single coverage) and $12,800 (family coverage).[151] Small group exchange plans and new employer-sponsored plans "must limit deductibles to $2,000 for single coverage and $4,000 for family coverage."[152] People without employer health plans will be required to have an individual plan that provides all essential benefits through either a market exchange plan or government-sponsored program (e.g., Medicaid, CHIP, and TRICARE).[153] These benefits are extremely valuable to many Americans with disabilities, who previously have been denied health care due to a preexisting condition or because they could not afford the plans that permitted preexisting conditions, or who have declined treatments or received incomplete treatments due to annual and lifetime caps.

The US Supreme Court's decision in *National Federation of Independent Business v. Sebelius* upheld the ACA's individual mandate—that is, that everyone will be required to have health insurance, lest they be subject to a fine in the form of a tax.[154] However, the

Court struck down the provision that threatened to cut all of a state's Medicaid funding if it refused to expand Medicaid to a wider range of low-income adult Americans (i.e., living with incomes between 100 and 138 percent of the federal poverty level), many with disabilities. The Court left in place the expansion of Medicaid to a wider range of low-income children (ages 6 to 18).[155] The Court's decision also did not impact the ACA's new options for states "to provide home and community-based long-term services and supports for people with disabilities," and "to coordinate care for people with chronic conditions."[156]

NCD recommends that CMS and HHS develop short, closed-captioned informational videos (with text transcript and MP3) using visual representations and a low reading level, on a variety of topics, addressing the opportunities and challenges of the ACA for people with disabilities.

Regarding adults in states that do not expand Medicaid coverage to 138 percent, there will be an unintended gap in coverage under the ACA.[157] However, the ACA does provide tax credits and cost-sharing reductions for people with household income between 100 and 400 percent of the federal poverty level in order to buy qualified health plans on the insurance exchanges.[158] When the new health insurance marketplace begins open enrollment October 1, 2013, at present count 25 states will open their own exchanges, and the Federal Government will be operating exchanges for all others.[159] In contrast, 28 states presently are moving toward expanding coverage to adults up to the 138 percent of the federal poverty rate.[160]

NCD recommends that CMS and affiliates within HHS implement a public awareness campaign. The purpose will be to provide simple and accurate explanations about the benefits of state implementation of expanded Medicaid coverage in nonparticipating states.

Medicaid Managed Care

As the numbers of people with disabilities in the United States have steadily increased over the past two decades, so have the number of individuals enrolled in Medicaid managed care plans.[161] Today, more than two-thirds of the 70 million Medicaid beneficiaries receive at least a portion of their services through a managed care plan.[162] In addition, the number of states using Medicaid managed care for long-term services and supports (LTSS) jumped "from 8 in 2004 to 16 in 2012."[163] This acceleration in Medicaid managed care is attributed to three factors: anticipated Medicaid expansion in 2014 under the ACA, the economic recession and state budget shortfalls, and "the need to control outlays on behalf of the most expensive segment of the Medicaid population— seniors and people with chronic diseases and disabilities."[164]

Until recently, the vast majority of Medicaid managed care enrollees had been comparatively healthy children and working-age adults.[165] NCD recently reported that more than half of US states are now enrolling senior citizens and people with disabilities, as well as children with specialized medical needs, in Medicaid managed care plans.[166] A growing number of states also are offering dental care, behavioral health care, transportation, and pharmacy services through managed care plans.[167] These increases, though beneficial to many Americans with disabilities, are placing further strain on already limited state budgets.[168]

One common concern with implementation of the ACA is the bureaucracy being built around changes to Medicaid Managed Care. **Bob Harris**, president of CLASS in Massachusetts, an organization that serves 400 people with developmental and intellectual disabilities, described it this way:

> *Private insurers will be totally overseeing long-term care, including healthcare, such as day habilitation (a long-term Medicaid-funded program) for people with intellectual disabilities. … Insurers do not necessarily understand the nature and importance of how to fund, think and provide services for people with developmental and intellectual disabilities. ... Potential benefits in healthcare*

coordination for people with developmental and intellectual disabilities exist, but there needs to be better clarification of the process.

Specifically, stakeholders and their families are concerned about proposed changes in state Medicaid systems that may detrimentally affect the quality and availability of LTSS.[169] Information often is overwhelming or scarce, and people are frightened by what changes might mean to them personally.[170]

In a July 3, 2013, letter to Dr. Bruce Chernof, chair of the Federal Commission on Long-Term Care, NCD expressed concern about the lack of a coherent national LTSS public policy for all people with disabilities, the absence of a "single federal or Congressional program or committee responsible for LTSS management, funding, and oversight; fragmented and uneven nature of LTSS; absence of a single community point of access to LTSS for individuals with disabilities and seniors; and no clear portability across states."[171]

NCD recognizes that managed care implementation systems have the potential to "lead to important efficiencies in the delivery and financing of health care services," and to create a pathway toward higher-quality services and more predictable costs, but only if service delivery policies are well designed and effectively implemented.[172] Cost savings may vary.[173]

Managed care requires the state Medicaid agency to robustly engage with people with disabilities, family members, and provider networks. To ensure accountability, states must work in conjunction with the stakeholder community to develop quality measures relating to outcomes desired by home- and community-based services (HCBS) programs. To date, most quality measures used in managed care demonstrations have focused on acute care outcomes, rather than those relating to LTSS.[174] The National Quality Forum has the lead responsibility for endorsing health care quality measures.[175] Among the more than 1,500 measures approved to date, only a handful are related to disability services; they are related to behavioral health and early childhood development.[176] The lack of quality measurement for LTSS may severely affect the most

vulnerable members of the disability community. NCD urges CMS to prioritize this issue within the context of its reviews of managed care waiver and demonstration requests.

NCD recognizes there are substantial concerns in the disability and aging communities regarding DOL's proposed changes to the Companionship Exemption to overtime compensation under the Fair Labor Standards Act. Working in concert with the broad disability community, service providers, and DOL including ODEP, NCD facilitated meetings and discussion around this subject in August 2012 and January 2013. NCD recommends that the Office of Management and Budget (OMB) re-engage in further discussion in order to fairly balance the important and complex needs of both the service providers and the disability and aging communities, before proceeding with the final steps of the proposed rulemaking process affecting the Companionship Exemption.[177] NCD welcomes dialogue with the disability community, service providers, and OMB on these issues.

Mental Health Care

The United States is awakening to the realization that the infrastructure that maintains mental health services is in need of modernization. Stigma toward people with mental health impairments is commonplace,[178] and the overall shortage of quality mental health services to meet the needs of middle-aged Americans enduring the nation's slow economic recovery, people with more serious mental illness,[179] service members, and veterans is pervasive.[180] Progressively, the ACA will require all plans to include mental and behavioral health care.[181]

On June 3, 2013, NCD participated in a National Conference on Mental Health at the White House. The event brought together stakeholders from around the nation, including mental health advocates, educators, health care providers, faith leaders, members of Congress, representatives from local governments, and individuals who have dealt with mental health challenges. The focus of the conference was to discuss how to collaboratively reduce stigma and help the millions of Americans struggling with mental

health issues recognize the value of reaching out for assistance.[182] The President opened the proceedings stating: "The brain is a body part too; we just know less about it. And there should be no shame in discussing or seeking help for treatable illnesses that affect too many people that we love. We've got to get rid of that embarrassment; we've got to get rid of that stigma."[183]

Health care reform has been overshadowed by public and political responses to the tragic gun incidents in Connecticut and Colorado over the past year. There is great concern in the mental health advocacy and treatment fields "about the tendency to link mental illness and violence and about the further stigmatizing of people who have a psychiatric diagnosis."[184] Critical information that Americans with mental health disabilities are members of the larger community, who, with access, attention, and treatment, pose no greater threat to the community than any other segment of society, was the core message of a January 2013 NCD letter to Vice President Biden and his Task Force on Gun Control and Violence.[185] NCD affirmed its support for and recommended improved availability, quality, and affordability of mental health services and supports: "The principal challenge is that access to mental health services is already compromised by deep and enduring stigma about seeking and receiving mental health treatment. ... A basic fact endures: people with psychiatric disabilities are more often the victims of violence than they are the perpetrators of violence. We must recognize the risk of increasing one type of violence while we seek to reduce another type. ... [P]ilot programs have been developed across the country to better meet the needs of people when they have their first psychotic episode. These programs are community-based and help to address critical unmet needs. NCD encourages the Taskforce to advance policy recommendations in line with these models and the principles undergirding them."[186]

Furthermore, President Obama's 2013 plan to improve school environments includes quality coverage of mental health treatment, particularly for young people, but with recognition of the unfounded public fear of people with mental health impairments. Recently, the White House explained: "Though the vast majority of Americans with a mental illness are not violent, we need to do more to identify mental health issues early

and help individuals get the treatment they need before dangerous situations develop. As President Obama has said, 'We are going to need to work on making access to mental health care as easy as access to a gun.' The Administration is proposing steps to identify mental health issues early and help individuals get the treatment they need before these dangerous situations develop."[187] The Administration is calling on Congress to help schools hire up to 1,000 more school resource officers, school psychologists, social workers, and counselors, as well as make other investments in school safety. We also need to make sure every school has a comprehensive emergency management plan so they are prepared to respond to situations like mass shootings. In addition, the Administration is proposing to help 8,000 schools put in place proven strategies to prevent violence and improve school climate by reducing bullying, drug abuse, violence, and other problem behaviors.[188]

Though there has been growing awareness of the impact of stigma on access to services, greater attention is needed on the availability of quality services. A May 2013 report from the Centers for Disease Control and Prevention (CDC) found that suicide rates in the general population have surpassed motor vehicle accident deaths, and have increased to record highs among white Americans ages 35 to 64.[189] Dr. Ileana Arias, CDC deputy director, "noted that the higher suicide rates might be due to a series of life and financial circumstances that are unique to the baby boomers. Men and women in that age group are often coping with the added stress of caring for aging parents while still providing financial and emotional support to adult children."[190] Another factor contributing to this increase has been a sharp rise in overdoses of prescription painkillers among women ages 45 to 54.[191]

The nation has significant shortages in specialized mental health services, "community-based services, including mobile crisis services and peer supports" for people with serious mental illnesses.[192] This profound deficiency "means that these services are often available only to people who are in immediate crisis and who have already endured multiple hospitalizations."[193] The National Alliance on Mental Illness (NAMI), in its "Grading the States 2009" report card, in part, found (1) states insufficiently address

wellness and survival for people with serious mental illness; (2) public health insurance plans are inadequate for meeting the needs of people with serious mental illness(es); (3) private insurance plans often provide insufficient coverage for mental health and substance use disorders; and (4) most states lack plans for developing or maintaining the mental health workforce, critical data on mental health services, access to information for the general public, and long-term housing for people with serious mental illnesses.[194]

NCD recommends HHS's Substance Abuse and Mental Health Services Administration (SAMHSA) invest in and award "system of care" expansion grants to improve the availability, quality, and affordability of community mental health services, mobile crisis services, housing, and peer supports for people with serious mental illnesses, and to extend mental health preventative and maintenance care access and options for the general population.

Improved services and changes to state law are needed to prevent inappropriate involuntary commitment. In the often misunderstood area of psychiatric disability, **Tina Minkowitz**, president and founder of the Center for the Human Rights of Users and Survivors of Psychiatry and blogger on the "Mad in America" Web site, detailed what happens to underserved communities and people with disabilities who "fall through the cracks":

> *Efforts to end involuntary commitment and forced mental health treatment are not getting better. States adding outpatient commitment laws suggest that in many ways things are getting worse. The United Nations Special Rapporteur on Torture has called for an absolute ban on nonconsensual psychiatric interventions, and there is abundant evidence of the harm done by these practices. There are numerous alternatives to the medical model of mental health, including Soteria, Intentional Peer Support, and the Eindhoven model which is based on Family Group Conferencing. Resources need to be shifted to make these human rights-compliant models widely and commonly available; and we need to repeal laws that allow psychiatrists to incarcerate people and force them to take toxic drugs against their will.*

NCD further recommends SAMHSA, the Task Force on Gun Control and Violence, and stakeholders with disabilities including NAMI, develop a joint policy statement addressing the issues of gun violence, involuntary commitment, forced mental health treatment, and others, which balances the individual freedoms and civil rights of people with psychosocial disabilities with society's obligation and responsibility to protect all people.

Health Care for Veterans

The significant issues of health care for veterans presently overlap substantially with the mental health issues of the general public. However, because veterans ordinarily receive health care services from public veteran-specific programs[195]—how their health requirements are being met merits unique attention. Most veterans and their families receive health services from the Department of Veteran's Affairs (VA) or under the Department of Defense's (DOD's) TRICARE managed health care program.[196] Nationwide, 1 in 10 veterans under the age of 65 (1.3 million), however, does not have health insurance coverage.[197] One reason for this is that VA services are available only through VA providers, which are concentrated in urban areas and often are a great distance from veterans in rural communities.[198]

The ACA may provide coverage for many of these veterans who otherwise are uninsured or cannot avail themselves of VA services without health insurance.[199] A 2013 study from the Robert Wood Johnson Foundation concluded that approximately "535,000 uninsured veterans … could be eligible for Medicaid under the ACA if their state participates in the Medicaid expansion."[200] An eligible 174,000 spouses and 78,000 children of veterans may also qualify.[201]

Another access barrier to health care for veterans is the VA initial claims backlog. Lengthy waiting periods for VA decisions and ratings result in veterans delaying decisions about their health care, declining physical and mental health status, or being denied benefits in the absence of any decision.[202] DOD and VA have a lot of critical health information to communicate to one another, because of the substantial overlap

between TRICARE and VA services. Though they recognize the long-overdue need for a single electronic health record system, the two agencies have not been able commit to a system capable of handling integrated information needs.[203] NCD recommends that the President direct deliberate coordination and collaboration among the Departments of Defense and Veterans Affairs, and other relevant federal agencies, to implement a superstructure of secure, private, online information sharing for all veterans' health and benefit records—for the efficient provision and processing of each veteran's health care needs and to end the backlog of veterans' claims.

To date, the TRICARE and VA systems have been called upon to treat and manage the health care of 1.6 million veterans who served in Afghanistan or Iraq, and who are returning to civilian life with hearing and vision loss, mobility impairments, traumatic brain injury (TBI), post-traumatic stress disorder (PTSD), depression, anxiety disorder, and alcohol and substance abuse disorders. Rates for these injuries tend to be higher than in previous wars, primarily due to advances in lifesaving medical emergency treatments and improved equipment (e.g., protective body armor), which contribute to improved survival rates.[204] Hearing loss and PTSD are the top two disabilities in this population.[205] There have been high rates of vision impairments often simultaneously co-occurring with TBI.[206] Spinal cord and brain injuries account for about 20 percent of all injuries, and the number of amputations (about 6 percent of injuries)[207] exceeds that of the Vietnam War.[208]

In all, about 25 percent of veterans returning from service since 9/11 meet the criteria for mental health conditions, including diagnoses of PTSD, TBI, and other mental health difficulties:[209] 39 percent with likely alcohol abuse;[210] 253,330 cases of TBI (about 19 percent) as of August 20, 2012; 131,341 cases of PTSD (about 14 percent) as of December 7, 2012;[211] 14 percent with major depression; and 5 percent with TBI, PTSD, and major depression.[212] More troubling is data indicating 57 percent of those with probable TBI have "not been evaluated by a physician for brain injury," and only 53 percent of those with PTSD or major depression have sought mental health services.[213] A 2008 report from the RAND Center for Military Health Policy Research concluded that:

"[e]ven when individuals receive care, too few receive quality care. Of those who have a mental disorder and also sought medical care for that problem, just over half received a minimally adequate treatment."[214]

Moreover, suicide rates among both active-duty service members (who have and have not deployed overseas) and veterans have reached alarming levels. Among active-duty troops, there is on average one suicide per day.[215] Among veterans, that rate is about 22 suicides per day.[216] Notably, however, veterans committing suicide tend to be 50 years or older.[217]

NCD acknowledges the efforts of many federal partners to address the unmet mental health needs of America's veterans. Appropriate and effective health care is essential to full recovery and successful integration into the workplace, and for families that have been disrupted during service far from home. RAND recommends improving access to mental health services for veterans, recruitment and retention of mental health professionals, and encouraging both veterans and active-duty service members to seek care.[218]

Likewise, NCD recommends increasing the cadre of providers who are trained and certified to deliver evidence-based health care services to meet current and future health care needs of active-duty personnel and veterans, whenever and wherever they are needed; and to effectuate policies that encourage active-duty personnel and veterans to seek needed care.

Summary and Recommendations

Passage of the Affordable Care Act on March 23, 2010, and the Supreme Court decision upholding most provisions of the Act on June 28, 2012, combined with ongoing debates and concerns over the cost of Medicare and Medicaid have brought increased attention to health care coverage and services. Much fear and confusion remains within the disability community as to what expected changes in health care will mean with regard to

the supports and services that people rely on to live and work in their communities. NCD makes the following recommendations regarding health care concerns and issues;

- **3.1** NCD recommends that the Centers for Medicare and Medicaid Services and affiliates within the Department of Health and Human Services implement a public awareness campaign to simply and accurately explain the business case (i.e., the benefit to business) for state implementation of expanded Medicaid coverage in nonparticipating states. HHS should publicize its targeted time frame for beginning the campaign.

- **3.2** NCD recommends that CMS and HHS develop short, closed-captioned informational videos (with text transcript and MP3) using visual representations and a low reading level, on a variety of topics, addressing the opportunities and challenges of the ACA for people with disabilities by January 1, 2014.

- **3.3** NCD recommends that the Office of Management and Budget re-engage in further discussion with stakeholders and service providers within the disability and aging communities, in order to fairly balance the important and complex needs within these communities, before proceeding with the final steps of the proposed rulemaking process affecting the Companionship Exemption.

- **3.4** NCD recommends HHS's Substance Abuse and Mental Health Services Administration invest in and award "system of care" expansion grants by June 30, 2014, to improve the availability, quality, and affordability of community mental health services, mobile crisis services, housing, and peer supports for people with serious mental illnesses, and to extend mental health preventative and maintenance care access and options for the general population.

- **3.5** NCD recommends SAMHSA, the Task Force on Gun Control and Violence, and stakeholders with disabilities including the National Alliance on Mental Illness, develop a joint policy statement addressing the issues of gun violence, involuntary commitment, forced mental health treatment, and other issues, which balances the individual freedoms and civil rights of people with psychosocial disabilities with society's obligation and responsibility to protect all people.

- **3.6** NCD recommends increasing the cadre of providers who are trained and certified to deliver evidence-based health care services to meet current and future health care needs of active-duty personnel and veterans, whenever and wherever they are needed; and to effectuate policies that encourage active-duty personnel and veterans to seek needed care by January 1, 2015.
- **3.7** NCD recommends the President direct deliberate coordination and collaboration among the Departments of Defense and Veterans Affairs, and other relevant federal agencies, to implement a superstructure of secure, private, online information sharing for all veterans' health and benefit records—for the efficient provision and processing of each veteran's health care needs and to end the backlog of veterans' claims—by June 30, 2014.

CHAPTER FOUR: COMMUNITY INTEGRATION

Barriers to participation for people with disabilities take a variety of forms in all aspects of society—in some cases this might mean access to the physical environment, but increasingly it also means subtle and less obvious barriers to information such as the lack of accommodations in using communications technology. Other areas of concern stem from policy gaps to discrimination resulting in Americans with disabilities having less than equal access to education, transportation, political participation, or justice within the legal system.

Accessibility and inclusion of people with disabilities are not only objectives, but ultimately prerequisites for the enjoyment and application of other fundamental rights in bedrock areas like voting, participating in civil society, community living, and life activities from childhood to adulthood. When barriers to civic inclusion are removed and people with disabilities are empowered to participate fully in the community, the entire community benefits.[219] When viewed from this larger perspective, equal opportunity and greater accessibility benefit society as a whole.

Education

> *Given the relationship between education and the greater likelihood of employment, ensuring that students with disabilities receive a high-quality education has the potential to affect, not only the millions of students with disabilities currently being served by the K-12 educational system, but also those who subsequently exit the special education system. It is particularly important to ensure that students with disabilities who are "in the margins"—e.g., those with more significant intellectual disabilities and those identified as having emotional disabilities—are provided high-quality learning opportunities, consistent with UDL principles and effective use of technology.*

> – Joint statement of CAST leadership, Founder and Chief Education Officer **David Rose**, Ed.D., Chief of Policy & Technology **Chuck Hitchcock**, M.Ed., and Policy Analyst/ Research Scientist **Joanne Karger**, J.D., Ed.D.

K–12 Education

Decades after the passage of the Individuals with Disabilities Education Act (IDEA), many students with disabilities are still struggling in school. The doors to the schoolhouse have been opened, but public school systems have been resistant to changes that support all students in making progress in the general curriculum and ultimately graduating from high school with a diploma, not to mention prepared to enter the adult world of higher education and employment.

However, younger students, particularly those with intellectual and multiple disabilities, continue to be denied access to the general curriculum. Persistent use of self-contained classrooms keeps too many students out of general education classes, making it difficult for students to access grade-level subject matter and build relationships with peers.[220] Exclusion compounds this problem as students are denied the ability to engage in the same curriculum as their peers without disabilities year after year.

As a result, graduation outcomes for students with disabilities remain poor. According to 2008–09 data, only 10 states graduated more than 50 percent of their students with disabilities with a standard diploma. In 27 states, less than 40 percent of students with disabilities earned a standard diploma.[221] Failure to earn a high school diploma makes it difficult for students with disabilities to pursue postsecondary education and significantly undermines their ability to compete in the workplace for jobs that pay living wages. NCD recommends the Department of Education fund state demonstration projects that use evidence-based pedagogical practices and transition planning to increase the state graduation rate of students with disabilities who receive a standard high school diploma.

The challenge of postsecondary access for students with disabilities worsened in 2012 with the passage of federal legislation that prohibits students graduating with modified diplomas from receiving federal Pell Grants and federal student loans even for trade and career programs.[222] Under the new law, only students with regular diplomas or GEDs are eligible for federal financial aid. This locks many of these students who do not have the

resources to independently pay for vocational training (e.g., welding, child care, culinary arts) into a lifetime of poverty-level wages.

The implementation of the Common Core State Standards[223] represents new opportunities for public schools to redesign the general curriculum to be accessible to all students. According to the states engaged in developing and implementing the standards, "Common Core State Standards provide a consistent, clear understanding of what students are expected to learn, so teachers and parents know what they need to do to help them."[224] By adopting appropriate technology and adhering to the principles of Universal Design for Learning (UDL), schools have the opportunity to provide students with disabilities the ability to access grade-level curriculum, in regular classrooms, alongside their peers.

David Rose, Ed.D., founder and chief education officer, **Chuck Hitchcock**, M.Ed., chief of policy and technology, and **Joanne Karger**, J.D., Ed.D., policy analyst/research scientist at CAST, expressed in their joint response to our query:

> *What is needed is radical change to the educational system. In order for the goal of increased college and career readiness to be realized for all students, attention needs to be paid to addressing the needs of learners, including students with disabilities, who traditionally find themselves in the margins. Motivation to change the system is greatest at these edges, and the resistance to it, weakest. Most importantly, the same innovations that these students require will benefit the entire culture.*

The upcoming reauthorization anticipated in 2013 of the IDEA and the Elementary and Secondary Education Act (ESEA)[225] create new opportunities for the Federal Government to develop plans that expand access to standard diplomas and develop standards for rigorous, meaningful modified diplomas that provide eligibility for postsecondary training and financial aid. In addition, a shift in accountability systems to focus on student learning outcomes and general education access may enhance learning experiences for students with disabilities at little extra expense. The focus must shift to what works for students, and how they can flourish as elementary, middle, and

high school students who are prepared to transition into adulthood, postsecondary education, and the workforce.

NCD recommends the Department of Education work with Congress to reauthorize the IDEA and the ESEA, and to work with state departments of education to develop standards for rigorous, meaningful, modified diplomas that provide eligibility for postsecondary training and financial aid.

Transition of Youth with Disabilities

Transition services are required under the IDEA for all eligible students with disabilities. Their purposes are to "promote movement from school to post-school activities, including postsecondary education; vocational education; integrated employment (including supported employment); continuing and adult education; adult services; [and into] independent living or community participation."[226] By the time that the first Individualized Education Program (IEP) takes effect during the student's 16th year, the IEP must include appropriate, measurable postsecondary transition goals; a course of study; and a coordinated set of activities.[227] The goals, based upon the student's preferences, strengths, and interests, must succinctly describe what students would like to achieve once they exit high school, articulated in terms of education, training, employment, and independent living skills.[228] The development of a coordinated set of activities is designed to provide a long-range educational plan with specific strategies to help students move from school into the community.[229] These activities may include instruction, related services, community experiences, employment, postsecondary adult living, daily living, and functional vocational evaluation.[230]

Judy York, director of the Resource Office on Disabilities at Yale College, detailed how the snowball effect brought about by the lack of transition planning can disrupt life outside the classroom or workplace:

Transition planning is weak, at best, from high school to college, especially … the student plans to live on a campus (away from home and parents). I know it is supposed to be an agreement between vocational rehabilitation [and] local schools within their outreach but it is inconsistent. Training is needed for vocational rehabilitation counselors and special education teachers and administrators on what should be considered to forward plan when exiting high school and entry to college. It goes beyond the classroom needs—living needs are equally important and are often overlooked or assumed.

Section 504 of the Rehabilitation Act also requires the local educational agency to provide accommodations for students with disabilities who qualify for services under Section 504, and who otherwise are not eligible for IDEA services.[231] While the Department of Education (DOE) Office for Civil Rights is responsible for the civil rights enforcement of Section 504 with state and local educational agencies, DOE leaves implementation and compliance to the state level.[232] Consequently, there is no federal or state oversight, monitoring, or accountability for the services provided to students with a disability who have a 504 plan.[233] NCD recommends that the DOE Office for Civil Rights develop a framework for oversight, monitoring, and accountability of these services.

Higher Education and Training

People with disabilities including veterans continue to face integration barriers in their efforts to pursue higher education, which has become almost essential to open doors for full participation in society. Common barriers found on both public and private college and university campuses across the United States include the lack of accessible paths onto campus and to, into, and through buildings; failure of prompt snow removal; delay in providing accessible textbooks and readings; absence of closed captioning video materials and screen-reader-accessible documents; delivery of instruction in online formats without access to real-time captioning; lack of opportunities for participation of students with speech and fine motor impairments; delay in faculty providing accommodations; absence of visual and auditory alarms; absence of accessible workspaces in libraries, classrooms, and computer and science labs; segregated assistive technology devices such as computer magnifiers and screen-readers; class materials and university documents not in formats easily modified to large text, Braille,

text to speech, etc.; required university policies on inaccessible websites; lack of accessible restrooms, cafeterias, and dormitories; stigma and attitudes of faculty, staff, and other students, and more.

The availability of accessible learning materials, especially those presented electronically, is a central issue facing students with sensory and print disabilities in higher education. The Higher Education Opportunity Act[234] established the Advisory Commission on Accessible Instructional Materials for Post-Secondary Education Students with Disabilities (AIM Commission), and charged it with studying the barriers and providing recommendations for the improved accessibility of materials in postsecondary education.[235]

The AIM Commission's final report identified barriers, challenges, and suggested steps—including law and policy recommendations, market and technology solutions, and capacity building and demonstration projects—to remove obstacles that deny students with disabilities complete and equal access to higher education.[236] NCD recommends that the DOJ and DOE implement a Project Civic Access–like program[237] targeting inaccessibility in higher education, and entering into short-term settlement agreements for each institution to come into compliance.

Two high-profile law suits in 2013 also have taken up these issues. On May 7, 2013, the University of California, Berkeley and disability rights advocates announced they had reached a settlement agreement to "improve information access for students with print related disabilities."[238] Similarly, in *Authors Guild, Inc. v. HathiTrust*, addressing allegations of copyright violation brought by the Authors Guild, a Federal District Court ruled that the systematic digitization of copyrighted books owned by universities without authorization was protected by the fair use doctrine, in part, to provide access to people with print disabilities.[239] Facing an appeal in the Second Circuit, disability advocates filed an amicus (Friend of the Court) brief on June 3, 2013, in support of HathiTrust, in part relying on the AIM Commission's report:

> *. . . [P]rint-disabled students and scholars do not currently have the equal access to university library programs, including instructional and research materials as required by the ADA. In the absence of comprehensive digitization, such students and scholars will not be able to freely identify and peruse research sources, use tables of contents to navigate materials, or have access to resources with the same speed and efficiency as nondisabled peers. Rather, they will be stranded in the existing ad hoc system, depending on readers or narrated and unnavigable audiobooks, or waiting for item-by-item scanning and optical character recognition processing while their peers quickly assess, review, and absorb necessary research materials.*[240]

The outcome of the case is pending, but clear opportunity remains for progressive changes, including promotion of full integration during education and training and incorporation of accessibility features in technologies used in postsecondary settings. The AIM Commission's recommendations urge Congress to take action on key issues to "facilitate the incorporation of accessibility features in technologies used in postsecondary settings," including:

- establishing a process for creating uniform accessibility guidelines for industry and consumers;
- revisiting the components of existing copyright exception;
- assessing AIM's relationship to current research and instructional materials access, taking into account the rights of content owners; and
- re-emphasizing the importance of compliance with civil rights laws for institutions of higher education so that the needs of students with disabilities are more adequately addressed.[241]

A second significant issue in higher education involves the large influx of veterans with disabilities into college programs.[242] In a survey conduct by AHEAD of Disability Service Offices (DSO) across the United States, the 237 completed surveys identified 1,202 "Wounded Warriors" on their campuses.[243] Psychological and emotional disabilities accounted for the largest percentage of Wounded Warriors (34 percent of males, 11 percent of females). Students with health-medical (e.g., diabetes, epilepsy, AIDS),[244] burn, and mobility impairments accounted for 25 percent of male students and 5.2

percent of females. Learning disabilities accounted for 9 and 7 percent of male and female students, respectively.[245] Surprisingly, only 5 percent of males and less than 1 percent of female students were hard of hearing, and no students were reported to have visual impairments.[246]

Sarah Helm, Ph.D., coordinator of the Disability-Careers Office, University of Tennessee (Knoxville), spoke to NCD about some of the unmet needs of veterans with disabilities who use the GI Bill for higher education and training that can help them prepare for the modern workplace:

> *We need to do a better job of being proactive [for] student veterans with visible and invisible disabilities. On average there can be 400 students on campus [who are] coming to school on the GI bill. They need to know [the Office of Disability Services is] here. Students need to see something ... more outreach ... career development [options]. People want to work, be part of society, [and] earn a paycheck.*

A 2009 journal article identified additional unique challenges for DSOs in serving veterans with disabilities, namely involving disclosure, documentation, and accommodation. These issues include failure to self-identify, invisible disabilities, sources of documentation, and significant delays in acquiring documentation from the VA and other federal agencies. Veterans may be more reluctant to disclose their disability to the DSO than other students.[247] NCD recommends that the DOE and VA prepare best practice technical assistance resources for disability service offices in higher education that address the challenges of disclosure, documentation, and accommodation in serving veterans with disabilities and eliminate delays in acquiring documentation from the VA and other federal agencies.

Housing

Housing options for approximately 20 percent of all Americans with disabilities pose problems including poverty, accessibility, and even safety. Among 57 million Americans with disabilities, federal estimates indicate at least 500,000 are homeless including children, and perhaps 80 percent of them may be staying in homeless shelters or on the

streets.[248] National data also estimates that about 35.1 million households (one-third of all households) include one or more person with a disability.[249] Common characteristics of these households include that they are: most likely to be headed by someone age 65 years or older (60 percent) and to only include one or two people (75 percent), and 2.5 times more likely to be living near or below the federal poverty level.[250]

An estimated 3.4 million households that include a person with a disability are deemed "worst-case housing needs"—defined as "unassisted renters with very low incomes who have one of two 'priority problems' either paying more than half of their income for housing ('severe rent burden') or living in severely substandard housing."[251] Households that spend more than 30 percent of their income on housing (40 percent of households with disability, or 14.4 million)—a rate indicating the unaffordability of the housing—and considered worst-case are at increased risk of becoming homeless.[252]

Compared with a 70 percent homeownership rate among Americans generally, only about 10 percent of homeowner household heads have a disability.[253] Poverty and low income are key barriers to homeownership for people with disabilities, especially those with severe disabilities, which can be explained in significant part by higher rates of unemployment and underemployment.[254] Among homeowners 65 to 85 years of age, 94 percent have a disability.[255] Nursing and group home facilities house 2.2 million people with disabilities, including an estimated 125,000 people with severe mental illness (ages 22 to 64).[256] More than 300,000 people with psychiatric disabilities live in segregated housing.[257]

Among all people with disabilities, hundreds of thousands do not have full access to their home for lack of grab bars or handrails (788,000 households), accessible bathrooms (566,000), ramps (612,000), elevator or lifts to access (309,000), and inaccessible interior path and doorways (297,000).[258] About 11 percent of Americans have a chemical sensitivity that requires housing free of disabling environmental triggers.[259] NCD recommends that the Department of Housing and Urban Development (HUD) create small, low-interest loans and mini-grant opportunities for people with disabilities who

require home modifications such as grab bars, handrails, ramps, lifts, doorframe widening, and bathroom accessibility in order to continue living in their home, to move into housing, or to get in and out of the home safely.

On June 4, 2013, HUD issued guidance encouraging "public housing agencies … and other housing providers receiving federal financial assistance from HUD to partner with state and local governments to provide additional community-based, integrated housing opportunities for individuals with disabilities transitioning out of, or at serious risk of entering, institutions or other segregated settings."[260] While the new guidance does not outline specific requirements for federally funded housing programs, HUD stresses the "acute" need for community-based options for people with disabilities, as the effort to transition people with disabilities away from institutional settings and into community housing gains both momentum and acceptance.[261]

Transportation

Savannah Logsdon-Breakstone, a disability rights advocate, underscored the interconnected ways that multiple areas influence one's community involvement and overall quality of life:

> *It is hard to untangle issues like housing, transportation, and employment. They are so interrelated. Too often, Employment becomes even more of a challenge because the accessible transportation doesn't reach certain areas where there is affordable accessible housing. This also becomes a difficulty when talking about the other ways that people become involved in our communities—community clubs, faith communities, entertainment events, and volunteering opportunities all can become more difficult to attain when there is no transportation. Seeing as how the linking issue here appears to be transportation, I will focus on that.*
>
> *In some areas of our country, accessible transport—particularly for those who cannot drive and therefore cannot work to acquire an adapted vehicle—doesn't exist beyond medical appointments. The difficulties that isolation due to a lack of access to community events and interaction are, I believe, fairly well documented both within and without the population in question. This is a serious concern—our population tends to have difficulties with feelings of isolation and difference around the lack of access/welcoming attitudes within our communities even without the added difficulties of transportation access.*

A 44-year-old wheelchair user with spina bifida, who wished to remain anonymous, stressed the importance of accessible (and available) transportation options:

> *Though many cities have a paratransit system available as a result of Americans with Disabilities Act of 1990, there are many places where public transportation is lacking or inadequate. This is particularly true in suburban or rural communities. For example, if a paratransit system only runs from Monday to Friday between 8 am and 6 pm, this generally prevents people with disabilities from participating in their communities in the evening, weekends and on holidays. We need to create and prioritize public policies with broader mandates for transportation systems. The federal government might establish pilot programs on which states can build. Guidelines need to be more realistic in accommodating the transportation needs of people with disabilities. Funding could come from federal, state and local government and utilize local private contractors. There should also be greater support for new technology which utilizes the driverless car as is being pioneered in California and Oregon.*

Equal access, treatment, and independence are long-standing transportation issues. The failure of bus companies to provide people with disabilities bus service on equal terms as others without disability has been an issue for many people with disabilities across the nation. NCD recommends that the Departments of Justice and Transportation implement a Project Civic Access–like program targeting public transportation and paratransit systems that have high rates of complaints from local citizens for inaccessibility, for the purpose of entering into short-term settlement agreements for each transportation provider to come into compliance.

In June 2013, the DOJ and the US Attorney's Office for the District of New Jersey determined that DeCamp Bus Lines violated the ADA by requiring that passengers with disabilities provide 48 hours of advance notice to secure a wheelchair-accessible bus.[262] Passengers without disabilities did not have to provide any advance notice. The settlement agreement requires DeCamp to comply with all ADA requirements for accessible service, and not exclude people with disabilities from its transportation services.[263]

In June 2012, however, the US Court of Appeals for the Second Circuit overturned a Federal District Court decision that had required New York City taxi drivers to provide accessible vehicles. The Appeals Court held that ADA Title II "does not obligate the [Taxi & Limousine Commission] to use its licensing and regulatory authority over the New York City taxi industry to require that taxi owners provide meaningful access to taxis for [people] with disabilities."[264] The Court did rule that the Commission may not discriminate against people with disabilities seeking a license to drive a cab.[265]

Independent operation of motor vehicles has made headlines with regard to a 21st century opportunity for access to transportation for people with mobility and sensory disabilities. The Department of Transportation (DOT) released its current policy on automated vehicles on May 30, 2013, and identified actions at the state level to make autonomous vehicles accessible to passengers with disabilities. DOT's policy addresses the potential of this technology for people with disabilities: "Mobility for those with a range of disabilities will be greatly enhanced if the basic driving functions can be safely performed by the vehicle itself, opening new windows for millions of people."[266]

DOT also indicates that several states, including Nevada, California, and Florida, have enacted legislation that expressly permits operation of self-driving (sometimes called "autonomous") vehicles under certain conditions. These experimental vehicles are at the highest end of a wide range of automation including some safety features already in vehicles, such as electronic stability control.[267] The policy will provide states interested in passing similar laws with assistance to ensure that their legislation does not inadvertently affect current vehicle technology and that the testing of self-driving vehicles is conducted safely. DOT's National Highway Traffic Safety Administration plans to conduct research to support the development of potential technical requirements for automated vehicle systems. However, the feasibility of the research depends on receipt of new funding.[268]

Voting Participation

More than fifteen (15.6) million people with disabilities voted in the November 2012 elections.[269] Voter turnout was 5.7 percentage points lower than turnout for voters without disabilities, equal to about 3 million fewer voters with disabilities.[270] The rate of voter registration among people with disabilities was 2.3 percentage points lower.[271] Among employed voters, voting rates were the same for people with and without disabilities, "suggesting that employment helps bring people with disabilities into mainstream political life."[272]

Brad Williams, executive director of the New York State Independent Living Council (NYSILC), believed the greatest policy issue for Americans with disabilities is ensuring that people were afforded their civil right to vote. After the 2012 Presidential election, NYSILC conducted a post-election survey in which they concluded 30 percent of New Yorkers still faced challenges voting and 20 percent reported architectural barriers to voting at polling places. Williams recommended better training for poll workers and recruitment of people with disabilities as poll workers. He added:

> *If people with disabilities had full voting rights then we would not be facing [a] 31.2 percent employment rate … and a 28.6 percent poverty rate. … If the disability community was an organized voting bloc, then perhaps these issues would be addressed. Instead, we continue to be left out of the conversation and ignored by pollsters. ... It would appear as though people with disabilities in our state are only seen as those that have special needs, are considered a vulnerable population and need protecting.*

Williams described how NYSILC has tried to work with pollsters to get a disability question added and has not been successful. In addition, he described NYSILC's two years of unsuccessful advocacy to have a bill introduced that would acknowledge disability-run businesses as minority owned. He felt strongly that this lack of response was due to the disability community not being seen as a voting bloc.

Accessibility

Despite the passage of the Help America Vote Act (HAVA) in 2002, current data on voting accessibility shows slow and limited improvement for people with disabilities.[273] People with physical, sensory, or intellectual disabilities or mental illnesses/psychiatric disabilities, and veterans with acquired disabilities remain among those most vulnerable to voting accessibility issues, along with those in racial and ethnic minorities and people who are aging.[274]

Testimony provided at NCD's Policy Forum, "The Help America Vote Act Ten Years Later: Has the Law Accomplished Its Aim?" held April 23, 2013, clarified that voting accessibility challenges and concerns were still apparent during the 2012 presidential election.[275] NCD found that "just over a quarter of polling places [were] accessible [in 2012]."[276] The report to the US Election Assistance Commission and Research Alliance for Accessible Voting found 30.1 percent of voters with disabilities had difficulty voting at a polling place, compared with only 8.4 percent of voters without disabilities.[277] The most common issues were difficulties understanding how to use the voting equipment (68 percent) and reading or seeing the ballot (59 percent).[278] More than one-fourth of voters with disabilities (28 percent), compared with one-sixth of voters without disabilities (17 percent), cast their votes by mail.[279]

Random samplings of New York City polling places in 2012 found widespread inaccessibility, "and that disability relevant criteria were not used for polling place selection and … training for poll workers was inadequate to comply with [federal] law."[280] South Carolina polling place surveys attest to ongoing problems with access to curbside voting, parking, signage, entrance to polling places, and access to assistance when required.[281] Doug Lewis, executive director of the National Association of Election Officials, commented that polling center accessibility is better today than in the past. "But are we fully compliant with the law all over the country? No," he said. "There is a money crunch right now. When that happens, progress stops."[282]

NCD recommends that the US Election Assistance Commission and Research Alliance for Accessible Voting identify and provide technical assistance including small grant amounts to ADA Title II entities in high-poverty areas that have inaccessible polling sites—in order to create accessible sites.

Just prior to the 2012 election, the United Spinal Association and Disabled in Action won a major battle on behalf of voters who use wheelchairs and scooters or who have vision impairments. On October 19, 2012, a federal judge ordered the New York City Board of Elections to adopt and implement an effective barrier removal plan at polling sites.[283] On July 25, 2013, a class action lawsuit was filed under HAVA alleging that the County of Alameda, California, discriminates against voters who are blind and visually impaired.[284]

Specific Populations

The American Civil Liberties Union (ACLU) reports that prior to the 2012 federal election, "states across the country passed measures to make it harder for Americans— particularly African-Americans, [people who are aging], students and people with disabilities—to exercise their fundamental right to cast a ballot."[285] The ACLU cited examples among more than 30 states whose legislatures considered laws that would require shortened early voting periods, curtail assistance at the polls for people who indicate that need, and/or require voters to present government-issued photo ID in order to vote.[286]

In a related report, Kimberly Leonard's 2012 article in *The Atlantic*, "Keeping the Mentally Incompetent from Voting,"[287] on "mental competency" laws raises additional concerns about whether such laws are outdated.

Voting accessibility problems and challenges can be magnified for veterans who are rehabilitating from the impact of combat injuries. Recently injured veterans may experience difficulty with inaccessible polling places, overly complex ballot design and voting technology, keeping track of progress while engaged in voting tasks, and grasping

and manipulating technology due to TBI, PTSD, upper and lower body injuries, and spinal cord injuries.[288]

The need to improve voting access transcends vulnerable populations, disability types, and civilian or military status. Funding is needed for HAVA compliance monitoring, education, and training of voters and poll workers.

Home- and Community-Based Long-term Services and Supports

Home- and community-based long-term services and supports provide people with disabilities and chronic health conditions with choices, control, and access to quality community services that support their independence, health, and quality of life.[289] Without these services, many people with disabilities are unnecessarily confined to institutional long-term care settings often at a distance from their community, family, and friends. The US Supreme Court's *Olmstead* decision requires states to provide these services "in the most integrated setting appropriate to the needs of qualified individuals with disabilities."[290]

For all people with disabilities who age at home, the sustainability of long-term supports and services merits careful consideration. Our nation has a long-standing commitment to ensuring that individuals are afforded the opportunity to live in the community with the appropriate supports, while addressing the growing costs associated with long-term service and supports.[291] NCD acknowledged the many complex issues in its report, "The State of 21st Century Long-Term Services and Supports: Financing and Systems Reform for Americans with Disabilities."[292]

> *NCD believes that America needs a coherent and comprehensive framework for its LTSS policies, programs, and funding based on five interrelated assumptions. First, that people who are elderly and people with disabilities both desire and deserve choices when seeking assistance with daily living that maintains their self-determination and maximum dignity and independence. Second, the current financing mechanisms (public and private) will become unsustainable in the near future without significant reform. The system must be affordable to all Americans regardless of income levels and must consider opportunities to leverage public*

and private support in new ways without impoverishing beneficiaries. Third, there is an opportunity with the changing demographic picture of the United States to explore the possibilities of a universal approach to the design and financing of supports that is responsive to individuals under the age of 65, as well as Americans over 65 who may or may not have disabilities, without sacrificing individual choice and flexibility. Fourth, formal and informal caregiving must be sustained, including examination of family needs and workforce recruitment and retention challenges. Fifth, the approach to quality must examine consumer direction and control of resources in addition to traditional external quality assurance mechanisms.[293]

Reinforcing the point that you don't have to be the person with a disability to have disability affect you, **Katie Arnold**, executive director of the Sibling Leadership Network, stressed the key role siblings often play in providing natural supports for people with disabilities throughout their life span:

Siblings often play a key role in providing natural supports for people with disabilities throughout their life. Yet, navigating the disability service system and getting support for themselves as siblings can be difficult and overwhelming. Addressing the needs of siblings will lead to better outcomes for families and people with disabilities. Siblings often have the longest relationship of their lives with each other and greatly impact each other. Siblings are uniquely positioned in the family to support their brothers and sisters with disabilities to lead self-determined lives. The peer nature of their relationship makes them well-suited to support each other throughout life in many areas including employment, voting, transportation, relationships and sexuality, health care, housing supports, and more.

NCD takes seriously the challenges and the opportunities inherent in achieving viable and sustainable home- and community-based long-term services and supports that fulfill the promise of the ADA and the *Olmstead* decision. NCD looks forward to the work that will be accomplished by the recently created Commission on Long Term Care, and the role of member Henry Claypool of the American Association of People with Disabilities. NCD recommends that public and private agencies and partners work together to articulate a coherent and comprehensive framework for America's LTSS policies, programs, and funding.

Information and Communications Technology

The accessibility of information and communications technology (ICT) for users with disabilities, especially those with sensory, reading, fine motor, intellectual, attention, concentration, and speech impairments, has become essential for community inclusion.[294] These technologies are already or rapidly are becoming integrated into every aspect of American society.[295] Disability civil rights attorneys, who as members of the Disability Rights Bar Association share successful legal strategies,[296] have collaborated with the National Federation of the Blind, National Association of the Deaf, and other advocacy groups to win far-reaching settlements and class actions.[297] These legal initiatives are positively directing the application of ADA Title III and Section 504 to higher education, online public accommodations, and e-readers and other smart ICT devices.[298] It reasonably may be expected that the DOJ's proposed ADA Title II and III Web site accessibility regulations and the DOL's airport Web site and kiosk accessibility regulation will be issued as final regulations in the year ahead.[299] NCD recommends DOJ and DOT publication of the final rules for Title II and III Web and airport Web and kiosk accessibility within the next year.

New challenges and opportunities lay ahead for the disability community in this field. The proliferation of free massive online open courses (MOOCs), which have not been assessed for their accessibility, now is moving into the for-profit education realm.[300] On June 27, 2013, the United Nations (UN) reached another significant development to the benefit of people who are blind, visually impaired, and print-disabled.[301] An agency of the UN, the World Intellectual Property Organization (WIPO)—"dedicated to the use of intellectual property (patents, copyright, trademarks, designs, etc.) as a means of stimulating innovation and creativity"[302]—approved a landmark treaty in Marrakesh, Morocco, to facilitate access to published works by people with visual impairments and people with print disabilities.[303] The treaty addresses the territorial laws applying to copyright as they affect accessible formats and sharing of works across national borders.[304] The United States has been a member of WIPO since 1970, and is eligible to become a signatory member of the treaty.[305]

Accessible Currency

In *American Council of the Blind (ACB) v. Paulson*, the DC Circuit Court of Appeals ruled that American currency discriminates against Americans with vision, learning, and other disabilities.[306] The Court remanded the case to develop a solution. Since that time, the Bureau of Engraving and Printing (BEP) has been working in concert with the Department of Justice and the Federal Reserve to devise a solution that will enable all Americans to use paper currency with facility, security, and confidence.

Unprecedented increases in the number of Americans with vision disabilities, due to the aging demographics of American society and significant increases in combat injuries affecting sight among American veterans, make this an issue of pressing urgency.[307] The US Department of the Treasury, DOJ, and BEP have been working through the intricacies of producing tactile US currency.[308] In its 2012 Progress Report, NCD reported that BEP "anticipates finalization within the near future of the shape and type of tactile symbol to be affixed"[309] on bills larger than one dollar. NCD recommends that BEP complete its research and set a timetable for commencement of production of tactile currency.[310]

BEP has commenced a three-pronged approach to render currency accessible, including continued use of contrasting inks and raised numeric features, development of a tactile symbol to be affixed to bills after completion of the anticipated redesign of the 100 dollar bill, and development and distribution of currency readers.[311] While little progress toward introduction of tactile currency has been made, a recent publication by the BEP suggests that that the redesign of the 10 dollar bill, slated for introduction in 2019, may contain the first tactile feature.[312]

The reason for the delay in producing tactile currency thus far has been attributed to many factors. Despite collaborative efforts and willing engagement among the relevant agencies, BEP recently informed NCD that they still are exploring various options for a

tactile feature on US currency.[313] BEP provided NCD with details regarding the complexity of the task and the steps involved in currency redesign, including collaboration with the Federal Reserve, Anti-counterfeiting Commission, and the Secret Service, among other challenges involved in rendering an estimated 32.6 billion pieces of American currency tactile. BEP referred to standards for manufacturing, processing, and production, and coordination with manufacturers of cash handling equipment and the Federal Reserve Board to limit disruption to banking and other cash handling and processing operations, among other detailed consideration.[314] Efforts to produce and distribute currency readers are ongoing, and the currency reader program is expected to launch shortly.

While the challenges and complexities of adjusting American currency continue, other countries are succeeding in making meaningful transitions,[315] and the number of Americans who cannot use money continues to grow. NCD anticipates continued collaboration with the BEP, Federal Reserve, and other agencies in an effort to seek meaningful progress toward actual transition to fully tactile currency in the foreseeable future, and to assist in the introduction of the first fully tactile currency.

Summary and Recommendations

Americans with disabilities continue to face barriers to community participation in all aspects of society. When barriers to inclusion are removed and people with disabilities are empowered to participate fully in the community, the entire community benefits. Viewed from this larger perspective, NCD makes the following recommendations:

- **4.1** NCD recommends the Department of Education fund state demonstration projects that use evidence-based pedagogical practices and transition planning to increase the state graduation rate of students with disabilities who receive a standard high school diploma by 10 percent over three years.
- **4.2** NCD recommends the Department of Education work with Congress to reauthorize the IDEA and the ESEA by June 30, 2014, and to work with state

departments of education to develop standards for rigorous, meaningful, modified diplomas that provide eligibility for postsecondary training and financial aid.

- **4.3** NCD recommends that DOE Office for Civil Rights develop a framework for oversight, monitoring, and accountability of the services provided to students with a disability who have a 504 plan by June 30, 2014.

- **4.4** NCD recommends that the DOJ and DOE implement a Project Civic Access–like program targeting inaccessibility in higher education, and entering into short-term settlement agreements for each institution to come into compliance.

- **4.5** NCD recommends that the DOE and Department of Veterans Affairs prepare best practice technical assistance resources for disability service offices in higher education that address the challenges of disclosure, documentation, and accommodation in serving veterans with disabilities and eliminate delays in acquiring documentation from the VA and other federal agencies.

- **4.6** NCD recommends that the Department of Housing and Urban Development create small, low-interest loans and mini-grant opportunities for people with disabilities who require home modifications such as grab bars, handrails, ramps, lifts, doorframe widening, and bathroom accessibility in order to continue living in their homes, to move into housing, or to get in and out of the home safely.

- **4.7** NCD recommends that the DOJ and DOT implement a Project Civic Access program targeting public transportation and paratransit systems that have high rates of complaints from local citizens for inaccessibility, for the purpose of entering into short-term settlement agreements for each transportation provider to come into compliance.

- **4.8** NCD recommends that the US Election Assistance Commission and Research Alliance for Accessible Voting identify and provide technical assistance, including small grant amounts to ADA Title II entities in high-poverty areas that have inaccessible polling sites—in order to create accessible sites.

- **4.9** NCD recommends that public and private agencies and partners work together to articulate a coherent and comprehensive framework for America's LTSS policies, programs, and funding.

- **4.10** NCD recommends DOJ and DOT publish the final rules for Title II and III Web and airport Web and kiosk accessibility by June 30, 2014.
- **4.11** NCD recommends that the Bureau of Engraving and Printing complete its research and set a timetable for commencement of production of tactile currency by June 30, 2014.

CONCLUSION

Strength in Our Differences summarizes the status of federal laws and programs serving an estimated 57 million Americans with disabilities, their families, and the diverse segments of the disability community. *Strength in Our Differences* acknowledges the fact that as a nation we are stronger, and as a people we are more able to respond to the challenges in the ever-changing world that we share, because of our diversity.

This report is derived from the diverse voices of the disability community, including interviews with knowledgeable consumers, advocates, and experts on disability programs, supports, and services from across the nation. The review and analysis of these interviews revealed three major characteristics:

- The interdependent nature of some issues affecting people with disabilities makes it difficult to isolate and discuss one issue at a time;
- Deep concerns remain about prospects for withstanding the economic recession, given the unique challenges that the majority of people with disabilities face; and
- The disability rights movement has yet to meet critical and unmet needs.

The narrative, data, and recommendations of the 2013 Progress Report are neither exclusive, nor comprehensive, but should be viewed as opportunities to identify work yet to be done, in conjunction with NCD's ongoing policy outreach and research, and in collaboration with the Administration, Congress, and other agencies that seek fulfillment of the Americans with Disabilities Act.

Although measurable progress has been achieved in many areas, including employment, education, and community living, resulting in an overall state of the disability union, which is more robust with increased opportunities and greater accessibility overall, critical challenges remain in order to make the most of the advances our nation has made. 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 now and in the future so that the strengths present in our differences can be both realized and utilized for the benefit of all.

APPENDIX

Supplemental information in this section represents the broad array of topics and perspectives covered by participants in NCD's interviews. These are excerpts primarily selected as examples of further comments on "What is the single most important public policy issue for Americans with disabilities in 2013?"

Marian Vessels, director, Mid-Atlantic ADA Center, serving Delaware, the District of Columbia, Maryland, Pennsylvania, Virginia, and West Virginia, stated that the primary public policy issue is the lack of full enforcement and education on the Americans with Disabilities Act (ADA).

> *Increased education and enforcement of the ADA is needed to assure that the goal of the ADA is realized, full inclusion of people with disabilities (PWDs) into American society. As a PWD and an educator on the ADA, I am too keenly aware that there is much to be done to assure that the ADA goals are realized.*

Vessels also mentioned the role of information in self-advocacy and partnerships at the federal level as examples of strategies to foster improvement.

> *Many individuals with disabilities, their families and advocates still do not know of their rights, and responsibilities under the ADA. These individuals are still not confident and knowledgeable enough to self-advocate, which is required for enforcement. ... More collaboration of federal agencies with their state counterparts is needed to enhance the local entities ability to enforce and or educate about the issues surrounding the ADA. EEOC should work more closely with the state human relations commissions. Assistant Attorney Generals should be working with ADA educators and advocates; Disability Rights Networks, CILs and SILCs, human relations agencies in ADA Centers—former [Disability and Business Technical Assistance Centers] (DBTACS)—and so forth to address regional ADA compliance issues.*

Aaron T. Baier, consumer and systems advocacy coordinator, Access to Independence of Cortland County, New York, spoke with an NCD member. His summary comments focused on the need for individual supports during various transitional periods. These periods may include the transition into and out of the various levels of service as well as the transition to adulthood, with challenges affecting all people with disabilities, across systems, and may require the coordination of services. Among critical relationships needed to improve collaboration and coordination strategies—involving the exchange of information that will benefit people with disabilities—are several examples identified by Baier: federal and state-level partnerships; schools and CILs with child welfare entities; special education and related service provider entities, and residential living facilities connecting with schools and community-based programs as transition supports.

Ann Hardiman, executive director, New York State Association of Community and Residential Agencies, for provider member agencies serving people with intellectual and developmental disabilities (IDD) stated:

> *The most important challenge is how agencies can help [people] with IDD to become integrated and accepted in the community. The economy has significantly impacted services. A crucial issue is the recruitment and maintenance of direct support services who are capable, skilled workers. Another important issue is employment for people with disabilities that fosters self-esteem and productivity. Communities need additional capacity to provide special services for special needs such as persons with autism or forensic backgrounds. ... Respect and recognition in the community for people with IDD is important. We need to keep a high level, a campaign almost, to educate and bring awareness to the public, using legal tools already in place, if necessary, to make sure this happens. ... Partnerships are all important. There should be support for states that need to transition away from congregate programs that have been developed as a step away from institutions. States need room to be innovative, thoughtful (not rushing), and money to invest. Incentives could be developed for independent living and capacity building around person-centered planning.*

Darrell Simmons, former diversity manager, currently in human resources organization development, MD Anderson Center, Houston, Texas, called the most important public policy issue the allocation of the US budget, including austerity measures also known as sequestration.

> *The vast majority of Americans with disabilities are among the poorest Americans due to unemployment, low employment [and] wages and/or in many cases a poor*

quality of life as it relates to health and the ability to keep up the pace of living and working in America. African Americans, Latinos, Asians/[Pacific Islanders] and American Indians/Alaska Natives with disabilities are the poorest of poor Americans with disabilities as evidenced by employment rates since the recession hit the US and global economies. Even those who enjoy decent wages, and good living conditions and quality of life are also impacted by budget allocations which affect the level and amount of assistance available for securing housing, transportation, health care, food, and other human services. ... Federal budget allocations directly or indirectly affect the above populations because they critically impact the level and quality of assistance available at the local, state and national levels since many of these jurisdictions depend on federal dollars to boost funding levels for state citizens.

Mike Collins, disability consultant and former executive director for NCD, identified the most important 2013 issue as diminishing access to, and the increasing costs of, health care for people with chronic disabilities. Furthermore, Collins explained:

This is exemplified by CMS policies regarding provision of durable Medical Equipment and its so-called competitive bidding process that has put many local providers out of business and routinely denies necessary Medical Devices and supplies to those who need them most. ... Many people with disabilities need to focus on their daily needs for Health Care Services and don't have the time nor the knowledge to get deeper into the policies that drive the increases in cost that they experience. If denied a particular product, or service, they often struggle to pay it out of pocket rather than trying to appeal the decision. This failure to appeal becomes part of the cost-saving philosophy in place for Health Care providers, as many of them routinely approve the initial denials once appealed. If Congress understood the full scope and impact of this problem, and would be willing to set aside the partisan bickering that consumes their time, there would be a possibility that many of the restrictive policies could be eliminated and approvals could return to the same level as was in place 10 years ago.

Katy Beh Neas, Easter Seals senior vice president, government relations, described key policy areas and issues for that organization.

The most important policy issue for Americans with disabilities in 2013 is increasing early and ongoing access to community-based services and long-term supports, such as health care, education, job training, housing, transportation, respite and transition services. Past policy decisions to address the country's fiscal challenges have eroded access to critical support services for individuals with disabilities. As you know, people with disabilities disproportionately rely on government services to live, learn and work in their communities. These services were created by government because the private marketplace had not met the unique needs of people with disabilities. ... Overall, funding for key discretionary programs that provide individuals with disabilities with the tools and supports they need to succeed have been cut or at best received stagnant funding over many

fiscal years. The across-the-board sequestration cuts will further limit access to and effectiveness of these critical programs. Future policy decisions related to both entitlement programs and discretionary spending could further damage the progress the disability community has achieved to ensure early and ongoing access to services and long-term supports. Easter Seals strongly believes deficit reduction proposals must take a balanced approach to prevent further harm to people with disabilities across this country. ... We especially encourage policymakers to target services to very young children with disabilities at a critical time in their lives and also to students with disabilities as they prepare for adulthood to ensure they receive the training and experience they need to be successful during their transition and throughout their lives.

ENDNOTES

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