

**Investing in Independence:
Transition Recommendations for President George W. Bush**

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Executive Summary

As we inaugurate the first administration of the 21st century, the Federal Government is poised to address long-standing challenges to its performance and service to Americans with disabilities. George W. Bush gave his commitment during his campaign that he and his Administration would work to “ensure that all Americans with disabilities...have every chance to pursue the American dream—to use more of their own skills and make more of their own choices. We must do everything we can to ensure that more Americans with disabilities can live independently, hold jobs, and take part in the life of their communities.”

In various campaign speeches and in his New Freedom Initiative (NFI), then-Governor Bush articulated a number of proposals addressing Americans with disabilities, including the following:

- A commitment to end discrimination through strong, steadfast support for and enforcement of disability civil rights laws;
- Full workforce integration of Americans with disabilities;
- Expanded access to technology for Americans with disabilities to increase opportunities for productivity, full participation, and independent living; and
- Increased access into community life for Americans with disabilities by pursuing strong and coordinated implementation of the *Olmstead* decision.

(See New Freedom Initiative (June 15, 2000)).

With strong, representative and experienced leadership and open, ongoing input from the disability community, the challenge to make the most of the opportunities facing us at the start of this new Administration can be met. The National Council on Disability (NCD) has completed civil rights policy evaluations over the past several years directly related to the disability policy areas addressed in the New Freedom Initiative. NCD invites the new Administration to draw on the research and studies conducted by our agency for information on how and where executive agencies can act to the maximum benefit of their consumers.

Individuals with disabilities, advocates, and parents are looking for vision and action from the new executive and congressional leaders to advance the independence, full participation, and productivity of people with disabilities. This transition document incorporates recommendations developed through a series of summits and forums held by NCD between 1996 and 2000. The outcomes of the 1996 national summit of 300 disability rights leaders on disability policy in Dallas, Texas are published in NCD's Report *Achieving Independence: The Challenge for the 21st Century* (July 26, 1996). Subsequent NCD meetings held last year, Think Tank 2000: Advancing the Civil and Human Rights of People with Disabilities From Diverse Cultures and the Civil Rights Retreat, collectively developed a strategic plan for more effective civil rights enforcement (i.e., *Closing the Gap: A Ten-Point Strategy for the Next Decade of Disability Civil Rights Enforcement*). Specifically, NCD believes that these transition recommendations will assist the new Administration to:

- Advance the federal commitment to quality education for all children, including children and youth with disabilities through strengthened compliance and enforcement of IDEA.
- Implement key recommendations identified by the Presidential Task Force on the Employment of Adults with Disabilities (PTFEAD) to significantly reduce the 75 percent unemployment rate among individuals with disabilities (See, PTFEAD's *Re-charting the Course: If Not Now, When?* (November 15, 1999)).
- Ensure that general education, health, workforce development, housing, and other programs include appropriate services to individuals with disabilities (especially in cases where authority to develop service systems has been substantially returned to the states).
- Establish a system of health care that supports individualized care needs of people with disabilities for continued work opportunities, prevention of secondary conditions, and long-term care supports allowing individuals to live in their homes or in the least restrictive environment.
- Take national and international steps to ensure access to technology and participation in the global technological economy.

- Preserve and enhance funding for programs that further inclusion, integration, independent living and economic self-sufficiency of individuals with disabilities through the next decade under the goals and spending limits of the Balanced Budget Act.
- Encourage adoption of universal design concepts and create timely guidance and mechanisms for ensuring continuous improvement to accessibility in the environment (i.e., physical structures and pathways, transportation, and technology).
- Establish a foreign policy that supports the goals of access, civil and human rights, inclusion, and poverty reduction for people with disabilities throughout the world.

The following pages present a rationale, strategies, and recommendations that NCD believes are essential to how President Bush and the new Administration can fulfill America's promise to its 54 million citizens with disabilities. NCD believes these recommendations are consistent with, and incorporate, President Bush's New Freedom Initiative.

Introduction

Ten years ago Congress passed and President George H. W. Bush signed one of the most significant civil rights laws since the Civil Rights Act of 1964—the Americans with Disabilities Act (ADA). In so doing, the nation opened its door to a new age for people with disabilities.

NCD first proposed the concept of an ADA and then published the original draft that was introduced in Congress in 1988 (See, National Council on the Handicapped, *Toward Independence*, pp. 18-21, February 1986; National Council on the Handicapped, *On the Threshold of Independence*, pp. 27-39, January 1988). The overall purpose of NCD then and today is to promote policies, programs, practices, and procedures that guarantee equal opportunity for individuals with disabilities of all ages and backgrounds, regardless of the nature or severity of the disability; and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society (Public Law No. 98-221, Title I, Section 142, Stat. 27 (1984), codified as amended at 29 U.S.C. Section 781).

Over the past three years, the National Council on Disability (NCD) has documented findings of the strengths and weaknesses in federal implementation and enforcement of civil rights laws (i.e., the Air Carrier Access Act (ACAA), the Individuals with Disabilities Education Act (IDEA), and the Americans with Disabilities Act (ADA)) through a series of civil rights evaluations, leadership summits, and grassroots community briefings. Each evaluation, leadership summit, and community briefing confirmed that despite great strides toward equality,

people with disabilities still confront major ongoing barriers of discrimination and suffer the consequences of weak federal enforcement, such as:

- National diploma graduation rates for students who receive special education and related services have stagnated at 27 percent for the past three years, while rates are 75 percent for students who do not rely on special education;
- Unemployment rates for working-age adults with disabilities have hovered at the 70 percent level for at least the past 12 years, while rates are in the low single digits for working-age adults without disabilities;
- Home ownership rates for people with disabilities are in the single digits, while rates for people without disabilities are about 71 percent; and
- Computer usage and internet access for people with disabilities is half that of people without disabilities.

Because of these persistent barriers, NCD believes that the President must set a standard of greater federal commitment to deliver on the promises of disability and other civil and human rights laws, including the disability specific proposals made during the recent presidential campaign. The vitality of the ADA, the IDEA, Sections 504 and 508 of the Rehabilitation Act, the Fair Housing Act, and the Civil Rights Act, to name just a few, depends in large measure on the long-term vision and leadership of the Federal Government.

What Needs to Be Done?

In May of 2000 NCD convened Think Tank 2000: Advancing the Civil and Human Rights of People with Disabilities from Diverse Cultures. This group of experts from diverse cultural, professional and disability backgrounds was charged with developing action steps for fully implementing disability rights laws at the community level for people from diverse cultures and other under-served groups. Within a month after this meeting, NCD convened a second group, the Civil Rights Retreat, to build upon the Think Tank 2000 plan of action and NCD's civil rights policy evaluations. These experts, also from diverse cultural, professional and disability backgrounds, were charged with mapping out the elements of a ten-year strategy for more effective civil rights enforcement.

The resulting ten-point strategy represents a collective effort by people from many diverse backgrounds to reach past their own community perspectives to understand and lend a

hand to one another on the road to full equality (NCD's draft *Closing the Gap: A Ten-Point Strategy For the Next Decade of Disability Civil Rights Enforcement* (August 10, 2000)). The following recommendations to President Bush, validated by several hundred Americans with disabilities during a series of 13 regional briefings conducted in summer/fall 2000, point the way to achieving the spirit and intent of America's civil rights laws for people with disabilities, their families and other advocates.

The President should exercise strong leadership to:

- **Install a disability-friendly Administration**—By appointing a highly talented and diverse Administration, including the appointment of significant numbers of people with disabilities in the White House and in key leadership positions throughout the Federal Government, the Bush-Cheney Administration will continue to elevate the standard established by previous administrations toward: (a) more readily unifying the nation on disability issues; (b) conducting broad and bipartisan education outreach on the goals of inclusion, independence and the vital importance of participation by people with disabilities in all aspects of American life; and (c) developing strategies, with input from the disability community, for engaging the disability and civil rights communities in key congressional and state government committees and other political activities geared to promote effective civil rights enforcement, policy development and implementation. In the White House, persons with disabilities should not only be installed in its personnel, domestic policy, and public liaison positions to benefit from their expertise on disability issues, but also in jobs involving broader policy and budget making capacities, such as those located in the Office of Management and Budget.

The Federal Government now employs more than 100,000 employees with some type of disability. Section 501 of the Rehabilitation Act established the Federal Government as a model employer for people with disabilities (See 29 CFR 1614.203(b)), and President Clinton instituted policies that promote accessibility, hiring, and promotion of federal employees with a disability (See, e.g., Executive Order 13078 (March 13, 1998)). The incoming administration should work hard to be supportive of these professionals and the policies that create equal opportunity for people with disabilities entering the workforce.

- **Give disability issues high visibility in the Administration**—Disability issues must have strong and visible priority at the highest level in the White House. The

President could appoint a top advisor/spokesperson such as those in his Domestic Policy Council to work with NCD on issues affecting disability policy. A function of this designee would be to coordinate and integrate activities of all White House "policy and political" offices, as well as all federal agencies responsible for administering and enforcing disability rights laws and policy. Another strategy could be to use the bully pulpit of the White House to call attention to critical civil and human rights issues facing the disability community.

- **Exercise bold leadership in developing federal strategy**—President Bush said in his campaign “ending discrimination is just the beginning of full participation” and promised that the NFI would “expand opportunities for people with disabilities to pursue the American dream.” Findings from NCD’s recent evaluations of key civil rights laws’ enforcement status indicate a need for comprehensive, cohesive federal leadership strategies for effective implementation of those laws (i.e., ADA, IDEA, ACAA).

The Bush-Cheney Administration should exercise bold leadership, initially, by developing a federal plan - with stakeholder input—for systematically implementing the NFI initiatives and NCD recommendations.

Next, they should lead an interagency effort—via the Interagency Disability Coordinating Committee—by all federal agencies having statutory enforcement responsibilities to coordinate their individual agency enforcement plans and develop a joint strategic action plan for vigorous overall implementation and enforcement of all disability rights laws (See, for example, NCD’s *Promises to Keep: A Decade of Federal Enforcement of the ADA* (June 27, 2000)). The administration should direct that both plans include specific outcome goals and performance indicators for measuring progress toward enforcement goals.

Finally, the administration should direct continual and substantial input from the stakeholders in the enforcement process, including disability, civil and human rights communities, in developing the action plans and monitoring their implementation. Putting in place a mechanism for citizen feedback and subsequent agency actions to resolve emerging concerns will be essential to show the administration’s accountability.

- **Require federal agency accountability, particularly for compliance, monitoring, and enforcement responsibilities**—The President should require federal enforcement agencies to disclose their enforcement plans and activities to

the public for feedback. Agency enforcement plans should be published periodically in the languages appropriate to their constituent communities. Stakeholder groups, including people with disabilities and their family members as consumer advocates, must be involved in giving feedback to the agencies on their enforcement plans, which should address the following:

- Agency enforcement missions, goals, and objectives, including Government Performance and Results Act (GPRA) outcomes measures for meeting agency objectives;
 - Budgetary and other resource allocations for disability civil and human rights enforcement;
 - Compliance monitoring and enforcement priorities, how they were established and the distribution of resources among enforcement activities such as compliance reviews, case findings, complaint processing and adjudication, post-adjudication monitoring, and others;
 - Mediation and settlement policies and factors influencing settlement outcomes, (i.e., case backlog, quality of available cases, number of referrals to mediation, etc.);
 - Sanctions imposed and other enforcement actions such as corrective action plans, compliance agreements, or withholding of funds, initiated in response to persistent noncompliance;
 - Coordination of enforcement activities, policies, record keeping and resources with those of other agencies;
 - Outreach methods for obtaining and using community input and feedback on enforcement methods and priorities; and
 - Criteria for determining when a civil or human rights law requires an amendment to successfully achieve its objectives.
- **Oppose any legislative or judicial weakening of disability civil rights protections by Congress or the Courts**—In an interview with John M. Williams from Business Week Online (June 21, 2000), George W. Bush said, “Let me lay this principle out. No law should undermine the Americans with Disabilities Act. The ADA must stand. The ADA is a good law. I want your readers and followers to know that George W. Bush, the son of President Bush who signed the Americans with Disabilities Act, fully supports the ADA in spirit and in law. I

would not do otherwise. There is a role to enhance the ADA: I want to make sure the law is fully complied with. The Federal Government has made a commitment to protecting civil rights. The ADA is a civil-rights legislation.” In the same interview, President Bush declared his opposition to the “ADA Notification Act (also known as the Foley Amendment) because it would “open up the whole law” to changes.

President Bush has said that in regards to the constitutionality of the ADA, which recently has been called into question by the U.S. Supreme Court, that he “believe[s] in the full force and effect of the ADA.” See Interview, *Id.* His father has called his decision to “embrace” and “press” for the enactment of the ADA while he was president a “landmark occasion” for him and all Americans and dedicated his “direct and personal interest in the defense of the ADA and the preservation of the important safeguards it provides to disabled Americans.” (Statement of Former President George H. W. Bush as Amicus Curiae in Support of Respondents, *The Board of Trustees of the University of Alabama et al. v. Patricia Garrett et al.*, No. 99-1240 S. Ct. (to be decided in spring 2001).

The Transition Period

One of the most critical and time-sensitive transition goals is to create an administration that looks like America; one that recognizes and includes 54 million Americans with disabilities. In addition to top-notch experience and credentials, presidential appointments must reflect the diversity of types of disabilities, talent, geography, culture, and socio-economic status of America. Former President Clinton has compiled a record of an unprecedented number of presidential appointees with disabilities. It is essential that the new administration act immediately to ensure that the more than seven thousand presidential appointees represent the broad diversity of America including people with disabilities. While President Bush has made a progressive start in the minority representation in his nominations of Cabinet members, there has been no public indication that individuals with disabilities were considered for head administrative positions. There has also been great concern expressed by the disability community about not being included in the current group of hundreds of transition advisors to the incoming administration.

Challenge and Opportunity

“Governor Bush believes that all Americans should have the opportunity to learn and develop skills, engage in productive work, choose where to live, and participate in community life. Although progress has been made over the last two decades -most prominently with passage of the Americans with Disabilities Act in 1990—Governor Bush believes that much more needs to be done. Governor Bush has proposed a "New Freedom Initiative," \$1.025 billion over 5 years to expand access to assistive technology, to integrate more Americans with disabilities into the workforce, and remove barriers to full participation in community life for all Americans. “

(Bush-Cheney 2000 Campaign Statement)

Strengthening Compliance With Disability Civil Rights Laws

The New Freedom Initiative promulgated by President Bush during his campaign addresses a number of civil rights issues that are directly related to NCD’s report recommendations. The following pages are a set of recommended activities that flow from the NFI and NCD’s recent series of civil rights reports.

Americans with Disabilities Act (ADA)

President Bush has affirmed that he will “support full enforcement of the Americans with Disabilities Act, and provide \$25 million in technical assistance to help small businesses comply with the Act.”

NCD acknowledges this commitment and also recommends that based on its extensive assessment study of the ADA (NCD, *Promises to Keep: A Decade of Federal Enforcement of the Americans with Disabilities Act* (June 27, 2000)):

- The Department of Justice should provide robust and assertive leadership for ADA implementation in developing a strategic vision and plan for ADA enforcement across the Federal Government;
- Federal enforcement agencies should engage in more outreach, training, and collaboration with the disability community on enforcement priorities;
- The Department of Justice should conduct outreach and training on the legal protections of the ADA in collaboration with the disability community, specifically targeting people with disabilities from underserved populations (i.e., those with severe cognitive and learning disabilities, and those living in institutions due to severe physical and mental disabilities).

Individuals with Disabilities Education Act (IDEA)

The New Freedom Initiative indicates that the Bush Administration “will work with Congress to increase funding for special education with the goal of meeting the federal obligation under the Individuals with Disabilities Education Act, focus Title I funds on earlier grades to identify children with disabilities, and invest \$5 billion over five years to establish the "Reading First" program.” NCD concurs with this initiative.

Among the many findings of NCD’s January 25, 2000 report entitled *Back to School on Civil Rights* was that enforcement of the law has too often been solely the burden of parents who must invoke formal complaint procedures and request due process hearings to obtain the services and supports to which their children are entitled under law. NCD made numerous recommendations for improving the federal track record and getting better results for children. Of these recommendations, NCD urges the new administration to take the following actions:

- Work with Congress to amend IDEA to provide the Department of Justice with independent authority to investigate and litigate cases brought under IDEA;
- The Office of Special Education and Rehabilitative Services in the Department of Education should continue to expand its initiatives to serve non-English speaking groups and/or people with limited English proficiency and create culturally appropriate training materials; and
- The Department of Education should establish and use national compliance standards and objective measures for assessing state progress toward better performance outcomes for children with disabilities and for achieving full compliance with Part B.

With respect to the last recommendation, NCD is presently working in collaboration with the Office of Special Education Programs (OSEP) and a group of stakeholders to review OSEP’s Continuous Monitoring Improvement System, and develop recommendations regarding performance benchmarks and enforcement triggers.

NCD has deep concerns regarding certain proposals to the new administration and Congress pertaining to (1) private school voucher plans; (2) regular testing of students; and (3) increased flexibility for states – such proposals have the potential of seriously undermining the education and civil rights of children with disabilities if they are unable to gain the provision of IDEA services and supports to eligible students with disabilities. Any “reform” of IDEA must also safeguard against exclusion of students with disabilities from services and/or supports on

disciplinary grounds (See, NCD's *Discipline of Students with Disabilities: A Position Statement* (May 1998)).

Air Carrier Access Act (ACAA)

In its February 26, 1999 report entitled *Enforcing the Civil Rights Of Air Travelers with Disabilities: Recommendations For the Department Of Transportation and Congress*, NCD found that the Department of Transportation's (DOT) efforts to ensure airline compliance with ACAA were inconsistent and largely ineffective. DOT's model for ACAA enforcement relies heavily on monitoring of complaints and voluntary compliance by air carriers. This approach does not emphasize traditional investigation and prosecution of complaints similar to other federal civil rights enforcement agencies. Even the formal complaint process focuses only on issues of broad public interest, so that individual complainants have no reliable administrative means to obtain satisfaction unless the airline voluntarily cooperates. Accordingly, NCD found DOT's approach is critically lacking in the key areas of compliance monitoring, complaint handling, and leadership by the Department of Transportation.

Research data show that a long-standing lack of resources has substantially limited DOT's leadership in addressing difficult compliance problems (i.e., providing lifts and other boarding devices, providing regular training of airline personnel, and ensuring that new aircraft meet accessibility standards). To remedy this situation, NCD recommends that the President Bush and the U.S. Congress ensure that DOT:

- Gives the disability community substantive input to designating priorities for allocating new DOT funding for ACAA enforcement.
- Targets persistent airline compliance issues for corrective action and monitoring;
- Investigates all complaints, levies civil penalties for pattern and practice violations, and grants damages to plaintiffs;
- Applies more vigorous enforcement, including increased penalties for violations;
- Is adequately funded for a credible enforcement program;
- Requires the airlines to track and report the numbers and types of disability complaints to DOT at regular intervals; and
- Greatly steps up the quality and quantity of education outreach to the public, especially to air travelers with disabilities.

Cultural Diversity

The United States consists of a diverse population and we must make a conscious effort to meet the needs of all our people. Through increased outreach to underserved and unserved people with disabilities across the country (e.g., people with disabilities who are African American, Native American, Hispanic/Latino American, Asian American, Pacific Islanders or who identify with other racial and ethnic groups), NCD has collected and reported first-hand information that disclosed a number of the barriers to full inclusion in society (See, NCD's *Carrying on the Good Fight: Summary Paper from Think Tank 2000—Advancing the Civil and Human Rights of People with Disabilities from Diverse Cultures* (August 23, 2000)). Our groundbreaking report *Meeting the Unique Needs of Minorities with Disabilities* (April 26, 1993) and a recent follow-up report, *Lift Every Voice: Modernizing Disability Policies and Programs to Serve a Diverse Nation* (December 1, 1999), provided data on interactions among cultural group, disability and factors such as poverty, opportunities for appropriate education or training, receiving information about services, including health care, transportation, housing and many of the other essentials for full participation in all aspects of society.

The Bush Administration must establish an inclusive agenda for America that makes ongoing and emerging issues that impact people with disabilities from diverse cultures an integral part of all work regarding federal agency program administration and implementation, public policy, and legislative/regulatory work.

As reported in NCD's *Achieving Independence*, disability leaders have called upon federal and state governments to invest resources in working with tribal governments and indigenous people with disabilities to ensure that all policies affecting people with disabilities are culturally appropriate and extend beyond the federal or state government to include tribal governments. Many federal policies, such as ADA, were not developed in conjunction with tribal governments; thus their applicability to indigenous people and tribal governments is still being delineated. In the future, Congress and federal and state governments should work together to ensure appropriate applicability of disability laws to tribal governments and Native Americans.

The following are recommended to effectively address cultural diversity issues among our nations citizens with disabilities:

- NCD has learned from grassroots witnesses that the best way to empower minorities with disabilities and their families to take full advantage of federal laws, programs, and services is to provide them with easy-to-understand, culturally appropriate information about what their rights are under various federal laws and how best to exercise those rights when a violation occurs.
- A federal interagency team should develop and implement a large-scale outreach and training program targeted to people with disabilities from diverse cultural backgrounds and their families that will provide such information directly to the target audiences through a series of forums, workshops, and seminars across the country. These trainings should be repeated on a regular basis so that new people are trained each year and materials routinely updated.
- This interagency team should work with disability communities, minority communities, other disability, minority, and religious organizations, and other interested organizations to develop a work plan, timetables, and appropriate consultation as it begins its work. In addition, a core group of people with disabilities from diverse cultural backgrounds and their family members should be recruited to help develop the written materials and programs that will be used for the trainings, translate them into different languages with awareness of the cultural appropriateness of terminology, and conduct the trainings once the materials are produced.

Increasing Independent Living

The three cornerstones of the independent living philosophy are consumer sovereignty, self-reliance, and political and economic rights. Essential features of the independent living service model include consumer control, a cross-disability emphasis (inclusion of people with all types of disabilities--mental, physical, and sensory), a community-based and community-responsive approach, peer role modeling, availability of a wide range of services, a community advocacy orientation and open, ongoing access to services. The independent living philosophy views disability as an interaction with the society and the environment rather than as a medical condition or physical or mental impairment and rejects the supremacy of professionals as decision makers.

This philosophy has permeated public policy and programs (e.g., for assistive technology, health care, housing, transportation, employment, to name a few areas) in the United States throughout the 1980s and 1990s. This trend will continue as more and more barriers to self-sufficiency and economic independence are removed from the forward paths of Americans with disabilities in the 21st Century.

Assistive Technology Act

Through his New Freedom Initiative, President Bush has committed to “increase access to technology for Americans with disabilities and expand opportunities to function, learn, and live independently, by: a) tripling the Rehabilitative Engineering Research Centers' budget for assistive technologies, b) creating a new fund to help bring assistive technologies to market, and c) increasing tenfold the funding for low-interest loan programs to purchase assistive technologies. NCD endorses these efforts.

In addition, as a result of its research work, NCD recommends that:

- The Department of Education and Department of Health and Human Services ensure adequate support for assistive technology competency development within and across a variety of personnel preparation and training programs such as instructional technology, computer sciences, information sciences, special education, rehabilitation counseling, social work, medicine, nursing, and related services (occupational therapy, physical therapy, speech-language pathology, and audiology) (See, NCD’s *Federal Policy Barriers to Assistive Technology* (May 31, 2000)).
- The administration and Congress ensure that the Health Care Financing Administration (HCFA) revises the Medicare and Medicaid definitions and description of "medical care," "medical necessity," and "durable medical equipment" to broaden the range of assistive technology provided.

NCD’s Technology Watch advisory committee assists NCD in monitoring, analyzing, and promoting assistive and information technology access issues. For example, it recommended that the Federal Communications Commission (FCC) more clearly articulate the legal requirements under ADA, IDEA, and the Rehabilitation Act that are applicable to the schools, libraries, or consortia that apply for its “e-rate” program that provides discounted rates for telecommunications services and technologies to eligible schools and libraries under the FCC’s Universal Service program. As a result, FCC revised the application to include a reminder of the applicability of these laws. NCD is also currently conducting a study of federal

enforcement of key laws (i.e., ADA, Section 255 of the Telecommunications Act of 1996, and Section 508 of the Rehabilitation Act) as they relate to information technology (IT). During the nine-month study, NCD will examine federal entities responsible for implementing those laws that protect the rights of persons with disabilities that relate to accessible information technology. A report will be published in 2001.

Health Care

The October 2000 release of a Harvard Medical School-led study funded by the U.S. Agency for Healthcare Research and Quality reported that people enrolled in managed health care plans from locations with relatively high percentages of residents on welfare or who were African American or Hispanic received generally poorer quality health care than people with other demographic characteristics. This information is consistent with findings from previous studies and is important to the disability community because of the linkages between poverty, disability, and patterns of inequality of benefit for underserved populations in our country.

NCD has consistently addressed concerns about health care for people with disabilities in its reports. (See, e.g., NCD's last two *Progress Reports*; *Achieving Independence*; *Disability Perspectives and Recommendations on Proposals to Reform the Medicaid and Medicare Programs* (November 9, 1995); and *Making Health Care Reform Work for Americans with Disabilities* (July 26, 1994)). Legislation to protect the rights of all people with disabilities and their families who need access to quality health care has not been enacted by the 106th Congress. The primary area of controversy among proponents and opponents continues to focus on how to define and who determines "medical necessity." (For more information on this term, see e.g., <http://www.c-c-d.org/Medical.html>). NCD recommends that the incoming administration and the current Congress:

- Ensure that people with disabilities and their families will have access to the quality health care they require, and that people with disabilities receive necessary supports and services.
- Ensure the necessary funding for Ticket to Work and Work Incentives Improvement Act (TTWWIA) to continue state demonstration projects.
- Ensure passage of the Family Opportunity Act of 2000 (FOA). While the popular bipartisan bill had over 200 co sponsors in the House and Senate, it did not receive the necessary support for passage in the 106th Congress. The most critical provisions of the bill would allow states (state option) to offer Medicaid coverage to children with severe disabilities—physical or mental—who live in middle-income families. Passage of FOA promises improved health; the prevention of future disabilities; and a better chance for these children to live full and healthy lives with their families in their home communities. NCD strongly

urges President-elect Bush and the new Congress to pass this bill immediately at the beginning of the 107th Congress.

Finally, there is no clear national policy regarding assisted suicide, which is of great concern to Americans with disabilities (See, NCD's *Assisted Suicide: A Disability Perspective Position Paper* (March 27, 1997) as an example for national policy).

Housing

The New Freedom Initiative calls for a reform of HUD's Section 8 rental voucher program for people with disabilities to permit recipients to use up to a year's worth of vouchers to finance the down payment on a home. NCD supports such a recommendation, and any other home ownership initiatives considered by the new administration.

During the past decade, housing problems confronting people with disabilities and people with low incomes, and the lack of affordable housing have reached crisis proportions. According to HUD's most recent Annual Performance report, estimates of home ownership indicate that only two percent of all people with disabilities are homeowners and less than five percent of the 6.5 million people with disabilities living on Social Security Income (SSI)/Social Security Disability Income (SSDI) are homeowners. Nationwide, the income of a person with a disability receiving SSI benefits is only 24.4 percent of the average one-person income. At this income level a person with a disability receiving SSI must spend approximately 69 percent of his or her income to rent a modest one-bedroom apartment. Many people with disabilities live on limited or fixed incomes that prohibit accumulating enough savings to enable them to afford the costs of owning a home. These restrictions, added to institutional barriers and long-term stigma against people with disabilities, have precluded many financial institutions and government housing officials from viewing home ownership as a viable option for people with disabilities.

In addition, HUD released its Report to Congress entitled *Rental Assistance—The Worsening Crisis* in March 2000. The report found that the number of non-elderly adults with disabilities in families with worst case housing needs was between 1.1 million and 1.4 million.

NCD encourages HUD to create a national home modification fund for low-income people with disabilities, both renters and owners. HUD thereby will empower more people with disabilities to become homeowners or tenants in community settings.

NCD recommends that HUD reform the programs under which people with disabilities receive assistance with housing to ensure that these programs reflect the most integrated setting

requirement of section 504 and the independent living philosophy of the disability rights movement.

NCD also recognizes that the number one cause of a chronic shortage of appropriate housing for people with disabilities in America continues to be persistent and pervasive discrimination. NCD is currently evaluating the implementation and enforcement of the Fair Housing Amendments Act and expects to publish the results of its work this year.

Transportation

Transportation is a linchpin to independence for people with disabilities. Despite important progress in increased accessibility through funding and implementation of civil rights laws and federal technical assistance, transportation remains a major obstacle to their employment and participation in the community. Serious deficiencies in paratransit services and the irregular availability of accessible mass transit persist in many urban and rural communities.

President Bush has stated his desire to promote innovative transportation solutions for people with disabilities by providing \$45 million in funding for 10 pilot programs run by state or local governments in regional, urban, and rural areas. Additionally, he proposed to establish a competitive, \$100 million matching grant program to promote access to community-based alternative methods of transportation. NCD urges the new Administration to place the highest priority on measures that will ensure the availability and consistent operation of accessible public transportation to people with disabilities in every community in America. NCD and stakeholders should be consulted in developing and implementing accessible transportation initiatives to ensure that these measures truly have maximal impact.

Expanding Work Opportunity

Under ADA, workplaces are less forbidding than they once were. But many still find it difficult or impossible to get to the workplace. The Federal Government must press ahead with its work to reduce the astronomically high unemployment rate among people with disabilities in America. The costs to America of high unemployment exceeds \$300 billion annually when Supplemental Security Income or Social Security Disability Income, Medicaid and Medicare expenditures, and other direct costs of unemployment are considered (such as housing supports,

welfare and Worker's Compensation), and indirect costs of unemployment are factored in (such as lost taxes and productivity).

Former President Clinton recognized the need to modernize and coordinate federal policy to promote employment of people with disabilities by establishing a national task force on employment of adults with disabilities (PTFEAD)(Executive Order 13078 (March 13, 1988)), which was a key recommendation from NCD's 1996 report *Achieving Independence*. President Clinton also signed an Executive Order on January 10, 2001, establishing the President's Disability Employment Partnership Board to provide advice and information with respect to facilitating the employment of people with disabilities. The President's Committee on Employment of People with Disabilities is now operating under the Department of Labor (DOL) as the Office on Disability Policy. The new administration should ensure the continued coordination of these DOL entities in their work and provide disability employment advocates the opportunity to forge alliances for full inclusion of people with disabilities with the DOL agencies to create a coordinated and aggressive national policy to bring working-age individuals with disabilities into gainful employment at a rate equal to that of the general adult population.

Tele work

The New Freedom Initiative indicates that President Bush will provide \$20 million in federal matching funds to states to guarantee low-interest loans for individuals with disabilities to purchase computers and other equipment necessary to Tele work from home. In addition, the President has committed his support of legislation to make a company's contribution of computer and Internet access for home use by employees with disabilities a tax-free benefit. NCD urges the initiation and implementation of both efforts.

Ticket To Work—Work Incentives Improvement Act (TTWWIA)

On December 17, 1999, President Clinton signed TTWWIA. This landmark legislation gives people with disabilities the opportunity to move into employment and reduce their dependence on benefits and other assistance. It provides beneficiaries with disabilities both choice and expanded options in pursuing employment and employment supports.

The New Freedom Initiative states that President Bush plans to sign an Executive Order to support effective and swift implementation of the "Ticket-to-Work and Work Incentives Improvement Act" that gives Americans with disabilities the ability to choose

their own support services and maintain their health benefits when they return to work.

NCD endorses such executive action, and strongly urges the President to include provisions for accountability. This should include incentives to state and other grantees to demonstrate meaningful TTWWIIA grant results and consistent employment and quality of life outcomes for individuals with disabilities. NCD endorses the use of executive directives or other means for pressing the states to opt into the TTWWIIA program. Furthermore, NCD endorses the provision and use of consumer feedback mechanisms in TTWWIIA programs to maximize the impact of the initiative.

Youth

Despite advances in education, disability rights policy, the support of federal mandates, and increased funding of programs and initiatives that impact all youth, the post-school outcomes for far too many of our nation's youth and young adults are still poor. The current status translates not only into untapped talent and potential and unfulfilled dreams, but severely limits America's preparation of today's youth for full participation in tomorrow's society. The Social Security Administration and NCD's joint November 2000 report entitled *Transition and Post-School Outcomes for Youth with Disabilities: Closing the Gaps to Post-Secondary Education and Employment* brings attention to a persistent crisis situation for youth with disabilities documented by various national studies on post-school outcomes. A national initiative focusing on coordinated actions to address system reform is required. The new system must be effective in changing an antiquated system that has not accomplished widespread or favorable results from the beginning.

NCD urges the President and Congress to:

- Ensure that the tools (e.g., information technology, telecommunications) necessary for obtaining education and employment goals are provided to today's youth who will shape our nation's future;
- Remove federal-level administrative disincentives (e.g., conflicting federal policies between OSEP and SSA) for cross-cutting agency collaboration and coordination of efforts; and
- Ensure that relevant federal agencies and their state grantees, document and share information about what works, including integration of preparation for transition into daily school life and greater involvement of community resources at all levels, and innovation in ways of reaching diverse cultures, underserved and unserved populations (e.g., the

application of the Department of Education's Program Effectiveness Panel to all transition and school-to-work efforts); and

- Support the efforts of federal agencies to establish youth advisory committees comprised of nationally representative young people with disabilities for advice on issues impacting their lives.

Providing Access to Community Living

Americans recognize that all branches of the Federal Government must work together, as well as in cooperation with state and local government and the private sector, to eliminate barriers to full participation in civic life. Americans with disabilities should have full access to community-based care, quality mental health services, access to the political process, and access to ADA-exempt organizations such as religious organizations and clubs.

Community-based Care

In the summer of 1999, the U.S. Supreme Court handed down the landmark decision of *Olmstead v. L.C.*, 527 U.S. 581 (1999) The Court recognized that unjustified isolation and segregation of persons with disabilities in institutional settings is a form of discrimination prohibited by the ADA. The Court sent a simple yet profound message that long-term services and supports for people of all ages must be based on what is appropriate for and desired by the individual.

The New Freedom Initiative indicates that President Bush will sign an Executive Order supporting the most integrated community-based setting for individuals with disabilities, pursuant to the Supreme Court decision in *Olmstead*. NCD applauds this promise and strongly encourages the administration to expedite such an order. In addition, NCD recommends that people with disabilities have appropriate input to the allocation of the newly approved 50 million dollars in the Health Care Financing Administration's budget to assist with demonstration projects and a range of community-based activities throughout the life of the initiative.

Finally, NCD gives its strongest recommendation that the new administration and Congress work together from the outset to pass MiCASSA to meet the needs and desires of older Americans and citizens with disabilities to live in their own homes to the fullest extent possible.

Access to Political Process

In the wake of the recent Presidential election there are a plethora of legislative proposals for improving the elections process. NCD urges the new administration—and congressional leadership—to ensure that upcoming legislative vehicles include accessibility provisions in their package.

The National Organization on Disability/Harris Poll reports that 14 million Americans with disabilities—41 percent—voted in the last Presidential election, a substantial increase from 30 percent (about 11 million) in the 1996 election. However, people with disabilities vote at a rate that is 20 percent below non-disabled voters. Poor voter turnout among the disability population is partly a result of low registration rates—most disability service providers are in violation of the National Voter Registration Act (The Motor Voter Law), which requires them to offer voter registration to their clients (See NCD's *Implementation of the National Voter Registration Act by State Vocational Rehabilitation Agencies* (October 1, 1999). In local areas, disability issues seldom surface in election campaigns, and inaccessible polling places often discourage citizens with disabilities from voting. The Federal Election Commission reports that there are more than 20,000 inaccessible polling places nationwide.

President Bush indicated in his New Freedom Initiative his intent to create a National Commission to support improving access to the polls and ballot secrecy for people with disabilities. NCD heartily endorses such an effort as timely and pertinent to current voting reform efforts and recommends that the goals contained in this initiative should be integrated in mainstream efforts in voting reform. The new administration should work with a broad coalition of national disability, civil and human rights organizations to plan and help implement such a crucial endeavor.

Mental Health Services

Based on testimony received at its hearings, NCD believes that people with psychiatric disabilities, especially those living in institutions, may be deprived of their most fundamental rights systematically. Practices that would often be illegal if administered to people without disabilities are used routinely on people with psychiatric disabilities in the name of "treatment."

(See NCD's *From Privileges to Rights: People Labeled with Psychiatric Disabilities Speak for Themselves* (January 20, 2000)). NCD believes that drastic change is necessary in a number of systems that deal with this population to guarantee their fundamental rights as American citizens.

NCD calls on the President and Congress to ensure that people with psychiatric disabilities themselves are involved in a major way in making the policy changes that will enable them to claim their full citizenship rights.

NCD recommends that the use of involuntary treatments, such as forced drugging and inpatient and outpatient commitment laws, should be viewed as inherently suspect and as incompatible with the principles of self-determination. Public policy should be directed toward establishing a totally voluntary mental health system. NCD also recommends that aversive treatments, which involve the infliction of pain or the restriction of movement for purposes of changing behavior, should be banned.

The New Freedom Initiative calls for the creation of a National Commission to recommend reforms of the mental health service delivery system. Based on the research and public hearings into the concerns of people with psychiatric disabilities that include problems with the nation's mental health system, described above, NCD wholeheartedly endorses this and recommends that the administration adhere to the precept "Nothing about us without us" by including people who are psychiatric survivors as key members of that national commission. Most critically, the voices of psychiatric survivors would lend the commission the credibility necessary to garner public support for its recommendations.

Foreign Policy

NCD has worked cooperatively with the U.S. Department of State, providing advice and recommendations on how U.S. foreign policy can and must mirror our domestic policy agenda. The Department of State designated NCD as the official contact point within the U.S. government for disability issues.

NCD recommends that the Bush Administration act decisively to further the integration of people with disabilities in all spheres of U.S. operation, including the international arena. NCD strongly urges that the Department of State, under the direction of Secretary-designee Colin Powell, adopt an ambitious timetable for fully implementing the provisions of Section 504 of the Rehabilitation Act (See NCD's *Foreign Policy and Disability* (August 1, 1996)). Full implementation of this statute will eliminate many of the remaining barriers to full inclusion of people with disabilities, including discrimination against foreign travelers with disabilities and

the inclusion of people with disabilities in the programs sponsored by the Department of State overseas. In particular, NCD urges this administration to require that all foreign assistance programs ensure that people with disabilities are equal beneficiaries of such programs and are fully included in all programs intended for the general population (See, NCD's *Achieving Independence*).

Among national and international disability organizations, NCD has noted burgeoning support for an international convention on the human rights of people with disabilities. Despite the human rights conventions, declarations and resolutions of the past fifty years, the quality of life for people with disabilities in the majority of the world's countries has remained dismal. The U.N. Panel of Experts on disability issues, Rehabilitation International, the World Blind Union, World Federation of the Deaf, Disability Peoples' International, Inclusion International, and World Network of Psychiatric Users and Survivors have agreed to work jointly on a disability human rights convention, and the convention initiatives have also been endorsed by NCD's International Watch advisory committee.

Conclusions

This year, the Federal Government and states must implement a groundswell of new and effective education and habilitation/rehabilitation strategies to ensure that the overwhelming majority of the next generation of people with disabilities participates in the prosperity of work. Public policy and legislation must no longer force anyone into mere survival on income maintenance programs.

This year, we must provide a continuum of long-term care services to ensure that nursing home or other institutional care is not the "default solution." Access and adequate support to live where they choose is fundamental to people with disabilities to exercise their civil, political, social, religious, and cultural rights in society.

This year we must ensure that the new world economy, an economy already defined by technology, is also defined as an economy with the ability to unlock the potential of people with disabilities. Worldwide accessible technology is imperative.

This transition document reflects the large and small steps that should be taken by the new administration in the first 100 days—and beyond—to ensure that people with disabilities enjoy the full benefits of American citizenship and prosperity. Within these pages are the

incremental events, program endeavors, legislative proposals, and policy actions that comprise a coherent agenda for civil and human rights and access to society for people with disabilities.

These transition initiatives offer the new administration opportunities to reinvigorate federal enforcement of disability, civil, and human rights laws so that more Americans with disabilities and their families can realize the dream of equal access to full participation in American society. We must commit the leadership and resources to enforce our civil and human rights laws to ensure that protections in law are protections in fact.

Let the new administration mark a realignment of commitment from government, private sectors, and society to support the enormous energy of the grassroots movement for civil and human rights and access to society for individuals with disabilities.