

President's Committee for People with
Intellectual Disabilities



A CHARGE WE HAVE TO KEEP

A Road Map to Personal and Economic Freedom for People with Intellectual Disabilities in the 21st Century

2004

Disclaimer

This report, A Charge We Have to Keep: A Road Map to Personal and Economic Freedom for People with Intellectual Disabilities in the 21st Century, 2004, does not necessarily reflect the views of the U.S. Department of Health and Human Services.

In addition, although some of the information and data contained in this report were contributed by authorities in the field of disability, public policy, communication and related fields, the personal opinions that such contributors may hold or choose to express outside of this report do not necessarily reflect the views of the President's Committee for People with Intellectual Disabilities or the U.S. Department of Health and Human Services.



President's Committee for People with Intellectual
Disabilities U.S. DEPARTMENT OF HEALTH AND HUMAN
SERVICES Administration for Children and Families Washington, D.C.
20447

The President The White
House Washington, D.C.
20500

Dear Mr. President:

It has been a great privilege to support the leadership of an outstanding group of individuals who comprise the President's Committee for People with Intellectual Disabilities. This has been an extraordinary opportunity to serve your Administration. The Committee is a Federal Advisory Committee comprised of 21 appointed members and 13 ex officio members from departments of the U.S. Government and is supported by six staff members. The most important responsibility that has consumed the Committee since its members were sworn in on September 23, 2002, has been to advise you, Mr. President, on matters pertaining to people with intellectual disabilities that are of national concern.

At its first meeting, the Committee determined that it would organize its advice to you to the greatest extent possible within the conceptual framework of the challenges and goals outlined in the important New Freedom Initiative (NFI) for people with disabilities that you announced early in your Administration. The NFI clearly identified the critical problems that Americans with disabilities face. It states that many of them, including people with intellectual disabilities, "(1) have a lower level of educational attainment than those without disabilities, (2) are poorer and more likely to be unemployed than those without disabilities, and (3) remain outside the economic and social mainstream of American life." Providing core ideas to change this reality is what has motivated our Committee. Most of the members are self-advocates, parents, siblings or relatives of a person with an intellectual disability and know this reality well.

Mr. President, this document, A Charge We have to Keep: A Road Map to Personal and Economic Freedom for People with Intellectual Disabilities, is being submitted to you for our review and consideration. It is take time to change the decades-old policies of the 20th Century that have created is being submitted to you for your review and consideration. It will take time to change the decades-old policies that have created unnecessary barriers to opportunities for Americans with disabilities. The recommendations contained in this document are for the 21st Century and are not expected to be addressed simultaneously or within a short time-frame, but to be carried out judiciously over a period of time to allow for effective implementation. One recommendation, for example, is to permit citizens with disabilities, whether they are receiving or not receiving Federal benefits, and whether they are employed or not employed, to open and maintain savings accounts like other American citizens, without the current limits that are imposed upon them. We are determined to bring about the recommendations for the changes contained in this Report and have committed ourselves to this effort. Mr. President, this is in keeping with your New Freedom Initiative which you issued shortly after you were sworn into office in 2001.

Respectfully submitted,

A handwritten signature in black ink, reading "Madeleine Will", is written over a horizontal line.

Madeleine C. Will
Chairperson

A New Name and a New Century

The term "mental retardation" was coined many years ago to try to better describe a condition that many people have. Since then, attitudes about people with disabilities have changed to focus on abilities, personal growth, and how to improve independence. A new term was needed to reflect this change in attitudes. Perhaps more importantly, the term "mental retardation" has taken on negative connotations over the years. It has led to misunderstandings by adults, children, and the media about people who have intellectual disabilities and has resulted in the use of language that is often demeaning, hurtful, and humiliating to self-advocates and their families.



On July 25, 2003, in celebration of the 13th anniversary of the Americans with Disabilities Act, President George W. Bush signed Executive Order 12994 as amended, continuing the work of the Committee, but renaming it the President's Committee for People with Intellectual Disabilities (PCPID). With this Order, President Bush recognized that a new name and language make a difference in people's lives.

Windy Smith and Michael Rogers, self-advocate members of the PCPID, pushed for the name change to reflect a more human-focused approach:

"We talk about changing the way our government and communities see persons with intellectual disabilities. . . We should not hesitate to make a name change to start the process."

For these reasons, President Bush agreed with the Committee's recommendation that we needed to change our name. The name change is not just cosmetic. It signals a new beginning and a revitalization of the PCPID's mission in the 21st Century: to better recognize and uphold the right of all people with intellectual disabilities to enjoy a quality of life that promotes independence, self-determination, and participation as productive members of society.

The goals of the President's Committee include: the assurance of full citizenship rights of people with intellectual disabilities; the provision of all necessary supports to individuals and families; the reduction of the occurrence and severity of intellectual disabilities; and the promotion of the widest dissemination of information of models, programs, and services within the field of intellectual disabilities.ⁱⁱ

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Introduction

These are unprecedented times for people with disabilities. In the past 15 years, we have seen:

The Americans with Disabilities Act of 1990.¹

- Amendments to The Individuals with Disabilities Education Act of 1997

The Ticket to Work and Work Incentives Improvement Act of 1999.³

- The U.S. Supreme Court's Decision in Qlmstead v. LC.⁴

President George W. Bush's New Freedom Initiative.⁵

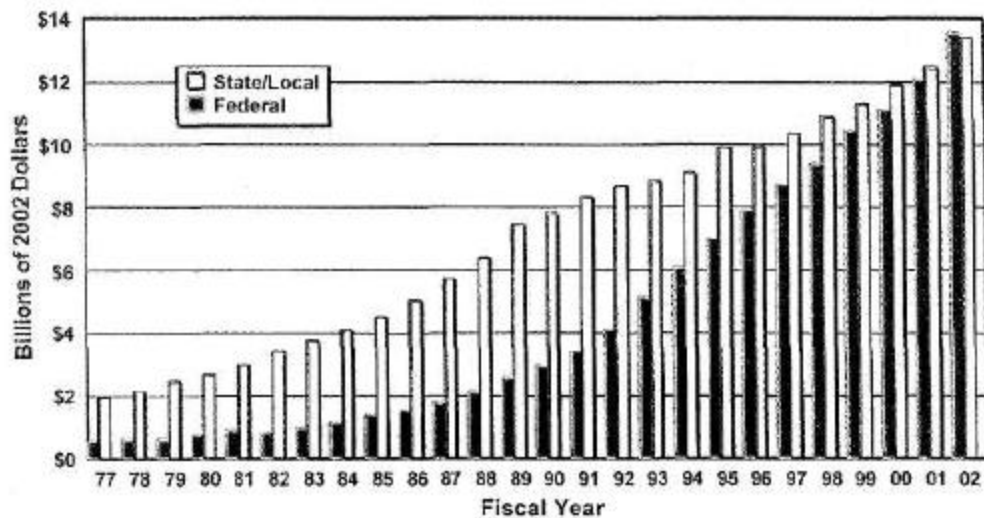
- The No Child Left Behind Act of 2001.⁶

The explosion of technological advances for people with disabilities.

Changes in public policy are beginning to remove barriers that force persons with disabilities to choose between work and health care. The Ticket to Work and Work Incentives Improvement Act allows states to provide continued Medicaid coverage to working persons with disabilities by allowing a buy-in option. Over two-thirds of the states are now in various stages of development and implementation of such buy-in options for workers with disabilities.

According to the 2004 report, The State of the States in Developmental Disabilities,⁷ federal funds constituted 23 percent of the total allocation for community services in 1977. By 2002, that proportion had increased to 50 percent of total community services spending. Between 1990 and 2002, federal spending, as a proportion of total community services spending, advanced from 27 percent to 50 percent. The growing contribution of federal funds in the financing of community services for persons with developmental disabilities, including persons with intellectual disabilities, across the nation is evident on the next page.⁸

FIGURE 4
UNITED STATES
TRENDS IN SPENDING FOR COMMUNITY SERVICES
BY LEVEL OF GOVERNMENT: FYs 1977-2002



The State of the States in Developmental Disabilities also shows that during 2000-2002, inflation-adjusted community spending in the United States advanced 17 percent.

These advances reflect our society's shift to a new paradigm of disability, based less on a medical model of treatment, impairment, and limitations and more on ability, independence, dignity, inclusion, and supports.

"The new paradigm of disability maintains that disability is an interaction between characteristics (e.g., conditions or impairments, functional status, or personal and social qualities) of an individual and characteristics of the natural, built, cultural, and social environments. It embodies the concept that a disabled person is no longer viewed only as someone who cannot function because of an impairment, but also as someone who may need or use accommodations in order to function."

Steven Tingus
Director, National Institute on Disability and Rehabilitation Research
Chair, Interagency Committee on Disability Research

People with intellectual disabilities, like all Americans, share the American dream to advance their social and economic freedoms, and more and more people are doing so successfully. Self-determination has become a nationwide movement that commands the attention of policymakers at every level of federal, state, and local government. There are increasing numbers of individuals with intellectual disabilities included in mainstream classrooms and post-secondary schools and training. Many adults are living independently or with supports in the community, marrying, having families, and working, just as other Americans. The self-advocacy movement has grown tremendously and there are now self-advocacy organizations in forty-four states.⁹

Although these examples represent significant progress, such progress is often not reflected in the life of the average person with intellectual disabilities. It is estimated that between seven and eight million Americans of all ages, about 3 percent of the general population, have intellectual disabilities.¹⁰ Taking the year 2002 as an example:

- Around 90 percent of adults with intellectual disabilities were not employed.¹¹
- Less than 1 percent of people with intellectual disabilities owned their own home.¹²
- 26 percent of youth with intellectual disabilities dropped out of school.¹³
- Fewer than 15 percent participated in post-secondary education.¹⁴
- Over 365,000 people were employed in sheltered workshops or were in day programs or prevocational services.¹⁵
- Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) were a major source of income for people with intellectual disabilities. In December 2001, there were almost 1.1 million adults and children receiving SSI payments based on intellectual disabilities. There were almost 600,000 receiving SSDI benefits.¹⁶
- At least 50,000 people with intellectual disabilities were on waiting lists for Medicaid waiver services for individual and family supports.¹⁷
- Over 700,000 people with intellectual disabilities lived with parents aged 60 or older.¹⁸

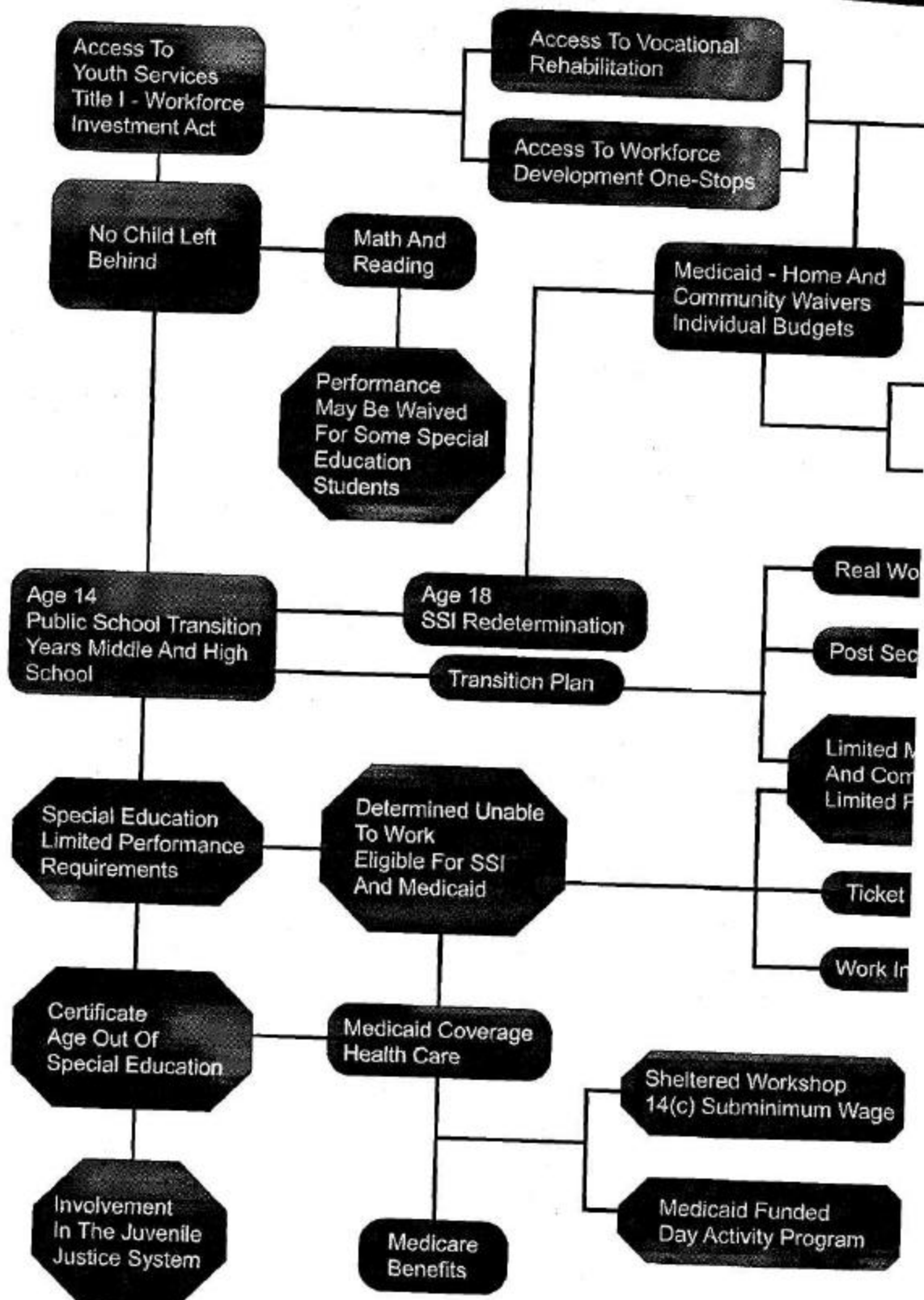
These dismal statistics describe a situation that would clearly be unacceptable for any group of people in this great nation in the 21st Century. Applied to such a significant portion of the population, they are simply intolerable and must be improved.'

ⁱ The PCPID considers the terms "mental retardation" and "intellectual disabilities" to be synonymous, covering the same population in number, kind, level, type and duration of the disability, and the need by individuals for specific services and supports. Thus, the American Association on Mental Retardation's definition for "mental retardation" serves as the definition for "intellectual disabilities." The PCPID is aware that there is a strong need for continued improvement in both quantity and quality of data collected and used in this report and other publications in the field.

DISABILITY



START



Especially serious is the fact that many, many individuals with intellectual disabilities can be, and want to be, productive members of society, but are dependent on programs that prevent them from being so. For example, the major support and health programs, SSI and Medicaid, require people to have such limited income and assets to receive these critical supports that they effectively prevent individuals from being able to earn and save sufficiently to improve their lives. The irony is that these limitations were intended to save taxpayer dollars, but they have the paradoxical effect of prolonging dependence and, ultimately, costing more.

The advances that have been made in recent years raise a different sort of problem. Numerous government programs, with overlapping missions and sometimes conflicting policy goals, have grown up alongside one another—both confusing intended beneficiaries and families and not delivering valued results. There are so many different programs administered by so many different agencies that people with intellectual disabilities and their families face a maze of overregulated, fragmented, sometimes conflicting, and always complex systems of benefits and supports. They are systems that are in critical need of realignment to encourage collaboration among agencies, with a blending of resources across funding streams, to achieve individual preferred outcomes. The "disability maze" depicted on the preceding pages illustrates the enormous complexity of the system.

The President's Committee for People with Intellectual Disabilities

The President's Committee for People with Intellectual Disabilities (PCPID) believes, passionately, along with the President, that the situation described in the preceding section is wrong, discriminatory, contrary to common sense and not good public policy. The Committee, at its very first meeting, decided that the President's New Freedom Initiative (NFI) would provide a great opportunity to focus on the specific needs of persons with intellectual disabilities. The NFI would provide guidance for our deliberations and recommendations. It was designed to further the progress made since the enactment of the Americans with Disabilities Act (ADA) by:

- Promoting full access to community life.
- Expanding educational opportunities.
- Increasing the ability of Americans with disabilities to integrate into the workforce.
- Increasing access to needed technologies.

Committee members also took guidance from the PCPID Charter, which requires the membership to:

- Evaluate and monitor the national effort to establish appropriate policies and supports for people with intellectual disabilities.
- Provide suggestions for improvement in: the delivery of services to people with intellectual disabilities, including preventive services; the promulgation of effective and humane policies; and the provision of necessary supports.
- Identify the extent to which various federal and state programs achieve the national goals for people with intellectual disabilities described in the preamble of the Executive Order for the President's Committee for People with Intellectual Disabilities, so as to have a positive impact on the lives of people with intellectual disabilities.
- Facilitate liaison among federal, state, and local governments, foundations, non-profit organizations, other private organizations, and citizens concerning people with intellectual disabilities.
- Develop and disseminate such information as will tend to reduce the incidence and severity of intellectual disabilities.

- Promote community participation and the development of community supports for citizens with intellectual disabilities.

During the period 2002-2004, the President's Committee met five times to consider how to address these challenges. We also formed five subcommittees that relate to the basic categories addressed in the New Freedom Initiative and the goals in our charter:

- Public Awareness
- Education and Transition from School to Work and Adult Life
- Employment and Asset Development
- Family Services and Supports
- Assistive Technology and Information

In September 2003, the Committee also hosted three roundtable discussions. The first examined the challenges and opportunities of self-determination. The second examined options to improve outcomes for youth in transition and adults seeking employment. The third examined issues of public awareness. Participants in the roundtables included representatives of, and experts in:

- Local, state, and federal government agencies;
- Non-profit organizations that represent constituents at the local, state, and federal levels, including self-advocates;
- Academic disciplines;
- Data collection;
- Public relations and communications;
- Health issues;
- Employment issues;
- Education; and
- Charitable organizations.

Based on our discussions, we concluded that there were a number of issues we should address and that are now reflected in our recommendations to the President in this report.

***Public Awareness.* Foremost, we concluded that there are enormous, pervasive problems in public attitudes towards people with intellectual disabilities—in schools, in the workplace, in communities, and in the media.**

It is a self-perpetuating cycle: children do not learn about the abilities, feelings, and value of people with intellectual disabilities, and adults retain their misconceptions, negative expectations, and stereotypical ideas. The media, often unintentionally, reinforce the stereotypes and prejudices.

The PCPID firmly believe that, unless and until we can start to change attitudes and misunderstandings about who people with intellectual disabilities *are*, progress in self-determination, community participation, education, and employment will continue to be measured only in inches instead of miles. The PCPID thinks that it is especially important to start to change attitudes in school-age children and employers so that the cycle can be broken.

Performance Management. **Several of the principles in our charter refer to our mission to advise the President about how successfully the federal government is serving people with intellectual disabilities in:**

- Policymaking.
- Measurement and accountability.
- Cooperation and coordination among federal agencies.
- Coordination with organizations and people outside the federal government.

Government agencies do not all have the same understanding and do not have coherent policies with respect to people with intellectual disabilities. For example, while one agency might open doors to employment, barriers may exist in another agency. Much of the positive, innovative work at all levels of government is really a function of individuals in government agencies seeking cooperation and collaboration on their own.

This Committee believes that most significant among the reasons that we have not seen sufficient improvement in the past is that there has been inadequate evaluation or measurement of the progress of federal agencies, and there is little accountability. In this report, we make a major recommendation for improving this situation that we believe the President could implement immediately.

Education and Transition from School to Work and Adult Life. **We also identified many issues related to education, from preschool through high school and beyond, to transition, adulthood and work, especially as they relate to the No Child Left Behind Act of 2001 and the Jobs for the 21st Century initiative, announced by the President, January 2004.**

The latter is a comprehensive plan to better prepare workers for jobs in the new millennium by strengthening post-secondary education and job training and improving high school education. Among the key issues identified by the PCPID were the need for better school accountability, appropriate standards for all students, curriculum improvements, more emphasis on reading instruction, more post-secondary education programs and training, including programs that permit students to enroll in high school *and* post-secondary programs, higher teacher qualifications and more intensive training.

Success in our schools is fundamental to the future success of individuals with intellectual disabilities as adults and we believe that it is the best way to significantly improve their employment prospects.

***Employment and Asset Development.* Employment and asset development for people with intellectual disabilities are critical issues.**

Current estimates indicate that around 90 percent of all people with intellectual disabilities are unemployed. Yet most are capable and interested in working and earning an income. With increased employment opportunities, they will not only earn income and improve their sense of positive self-worth, but will contribute to the nation's tax base and reduce their dependency on government.

A net result of employment would be the creation of a new social network for individuals with intellectual disabilities and their families — like a ripple effect, it would yield some new benefits not often recognized, known or readily available. The benefits would include a series of new and different networks, including associates, friendships and partnerships that arise from employment of their family member with intellectual disabilities.

Families would become more encouraged and hopeful of life in so many different ways through employment of their adult-child with intellectual disabilities. Correlated gains are anticipated when their parents, guardians or caregivers seek employment for themselves. Such gains translate into a significantly expanded pool of available citizens for employment and taxpayers in America. The overall impact on the nation's economy may be tremendous when one considers that one out of every ten American families has children or adults with intellectual disabilities.

Most of the relatively few adults with intellectual disabilities who are currently employed only hold part-time or temporary positions. Many earn salaries that are lower than the minimum wage and are not able to generate sufficient income to open a savings account. However, the few who are able to open a savings account often face barriers to asset development resulting from current policies and regulations.

As appalling as it may seem, there are parents and family members who are discouraged from establishing savings accounts in the names of their children or adults with intellectual disabilities. Selected government benefits programs limit participation of people with intellectual disabilities because of the nature of their disability and their receipt of government benefits.

The threat of falling deeper into poverty is quite real for those who contemplate employment if they become ineligible for disability benefits. There is a need to create a solid platform on which Americans with intellectual disabilities and their families can stand. That platform needs to consist of adequate employment opportunity and asset building without the threat of lost benefits.

Time is an essential component for both employment and savings to ensure success on-the-job and permit achievement of asset building capacity; otherwise, benefits are removed too soon and the risk of failure becomes too high for the individual and family. Given a solid chance to succeed, such individuals and their families will be able to strengthen America in countless ways.

***Family Services and Supports.* As previously noted, another one of the more significant problems we see is that many people with intellectual disabilities have to be poor and to stay poor to get the health care, interventions, and the services they need.**

For example, over a million Americans with intellectual disabilities rely on SSI for their subsistence and Medicaid for their health care. These programs create a cycle of dependence because they limit the income and assets a person can have without losing eligibility. We think that such policies isolate the individuals they are intended to serve and that they are not good public policy. Good policy would provide a means for saving and planning so that individuals can eventually reduce or even eliminate their reliance on these programs.

***Assistive Technology and Information.* Access to technology by persons with intellectual disabilities is essential to achieve the goals of the President's New Freedom Initiative.**

Technology and access to information play a central role in the lives of all people in our society, including persons with intellectual disabilities. Application of technology is vital to education, employment, independent living, and community inclusion. Federal agencies must collaborate to determine appropriate funding sources for technology to improve access and availability for persons with intellectual disabilities.

From our discussions, we also developed a common set of three principles regarding government responsibility:

Responsible government recognizes and supports individual self-determination as a preferred means to achieve new levels of customer satisfaction and personal and economic freedom.

Responsible government recognizes and rewards performance and results.

Responsible government recognizes and rewards innovation and collaboration within and across federal agencies and with the private sector.

These principles underlie all of our recommendations.

Name Change: An Early Success

One of the Committee's recommendations has already been implemented. On July 25, 2003, in celebration of the 13th anniversary of the Americans with Disabilities Act, the President signed an Executive Order that renamed the Committee. The President's Committee on Mental Retardation is now known as the President's Committee for People with Intellectual Disabilities. With this Order, President Bush recognized that a new name and language make a difference in people's lives. The name change is not just cosmetic. Words are powerful. Changing them can make a difference in people's attitudes, understanding, and self-esteem.

PUBLIC AWARENESS

"Having people with intellectual disabilities fully incorporated into the fabric of American Society should be the goal of every person in the United States. Not just because it is the right thing to do, but also because it is the wise thing to do. The story of America is written in the handwriting of a diverse people, many of whom were not included in the original Charter of this great nation. But, as each new group of Americans has gained recognition, acceptance and incorporation into our society, they have added immeasurably to the strength of us all."

"People with intellectual disabilities have a great deal to offer America. But, we must first recognize them as fellow human beings and citizens; accept their abilities and work for their mainstreaming into every aspect of American life from education to employment."

Neil Romano
President and CEO
America's Strength Foundation, LLC

"People with intellectual disabilities are first and foremost people; people with a full range of emotions, hopes and dreams. One of the most important responsibilities of the President's Committee for People with Intellectual Disabilities is to communicate the very real facts that people with intellectual disabilities can be educated, can work and can play an important part in our society. We must dispel the myths, which hold back a large segment of our citizenry, to the detriment of us all."

Kim Porter-Hoppe
Chair, PCPID Subcommittee on Public Awareness

Over the past quarter of a century, policymakers have been reacting to attitudinal and institutional barriers that have subjected children and adults with intellectual disabilities to lives of exclusion, isolation, and segregation. As previously mentioned, significant pieces of legislation, such as the Americans with Disabilities Act of 1990, Amendments to the Individuals with Disabilities Education Act of 1997, and the Workforce Investment Act of 1998,¹⁹ have shaped an emerging Disability Policy Framework.

Within this framework, our country is compelled to focus its energies on eliminating barriers to learning, work, and full participation in community life.

The Olmstead Supreme Court Decision called for expanded community-based services and community living choices for people with disabilities. This decision led the Bush Administration to exercise leadership by accelerating "Real Choice and Systems Change" at the state and local level. The Real Choice Systems Change grants were designed to help states enable people with disabilities to reside in their homes and participate fully in community life.²⁰ Despite these two important developments, evidence still suggests that there is a continued attitudinal lag toward individuals with intellectual disabilities. This is noted in the classroom and the workplace.

A recent major study of public attitudes revealed that the attitudes of the American public have not changed appreciably in the past 50 years, despite the many positive steps toward inclusion achieved through legislation and court decisions.²¹ The general public underestimates the capabilities of people with intellectual disabilities, perceiving them as less competent rather than more competent. Fewer than half of the public perceive them as capable of such skills as understanding a news event or handling their own money, and less than a third perceive people with intellectual disabilities as being capable of handling emergencies. It is apparent that the general public lacks an appreciation of the range of capabilities of people with intellectual disabilities, and, therefore, has low expectations of what they can do.

Given the public's misconceptions about the capabilities of people with intellectual disabilities, it is no wonder that they do not support inclusion, particularly in public schools. The results of the study showed that more than two-thirds of the public believe that children with intellectual disabilities should be educated either in special schools or special classes within regular schools. Furthermore, almost half of the public expect that if children with disabilities were included in regular classes, they would disrupt the classroom and make it harder for other students to learn. These findings are striking, given the major effort within public schools to include children with intellectual disabilities in the regular classroom.

Not everyone, however, holds negative attitudes. In fact, people who perceive people with intellectual disabilities as more capable support inclusion in work and school and expect few negative outcomes of inclusion. Therefore, in changing people's attitudes toward people with intellectual disabilities, we need to change how they think about such people, by demonstrating all that they are capable of. Attitudes and expectations of the public, in part, determine the degree to which children, adolescents, and adults with intellectual disabilities are able to learn, work, and live alongside their peers without disabilities.

At the Public Awareness Roundtable in September 2003, members met with experts in public relations and communications. Based on the discussions at the roundtable and our deliberations both within the subcommittee and with the full PCPID, we strongly recommend a public awareness campaign that targets school-age children and employers. The Committee believes that a high-profile, national effort could make a difference in changing attitudes in these important groups. There can never be any real, lasting progress unless we can begin to change attitudes in school-age children and break the cycle of children learning prejudice and growing into prejudiced adults. The PCPID is partnering with the Special Olympics to change negative public attitudes toward people with intellectual disabilities. The Committee applauds Special Olympics for their public awareness program that targets all school-age children.

Likewise, more employers need to understand that people with intellectual disabilities, like most people, can work and want to work. We need to educate employers about individuals with intellectual disabilities and the contributions they can make as workers in all employment settings.

The PCPID Committee recognizes that attitudes in the classroom and the workplace will not change overnight, even with a public awareness campaign. Many people and organizations have tried to make a difference over the past 50 years and there is no question that attitudes change slowly. However, the Committee further believes that past campaigns have made a difference and that it is essential to keep working for change.

The campaign should have a concise, specific message that promotes acceptance by changing the targeted audiences' understanding, expectations, and awareness of the abilities of children and adults with intellectual disabilities. It should portray people as equal and present a view that all belong. It must show people with intellectual disabilities so that they can be seen and heard. We also urge the President to participate, to help give the message the prominence it deserves. The President is in a unique position to broadcast this message.

Public Awareness Recommendations

The PCPID invites and encourages you, Mr. President, to participate as the Committee's spokesperson in a national campaign specifically targeted to school-age children and employers to change negative public attitudes toward people with intellectual disabilities. The campaign should include a variety of media, including public service announcements, print and television features, and a web directory to assist employers to identify individuals with intellectual disabilities who are seeking employment. The Committee is eager to collaborate and is prepared to partner with corporations that already have had positive experiences hiring individuals with intellectual disabilities.

The Committee is partnering with the Special Olympics to change negative public attitudes toward people with intellectual disabilities.

PERFORMANCE MANAGEMENT

"Governments should be results-oriented... Where we find success, we should repeat it, share it, and make it the standard. And where we find failure, we must call it by its name. Government action that fails in its purpose must be transformed or ended."

George W. Bush
Presidential Candidate
2000

"Integrating services in the income support-related programs is happening where strong leaders and able managers, as well as motivated staff, share a clear vision and have the energy and patience to make the vision real."

Mark Regan
Senior Fellow, The Rockefeller Institute

"For a parent of a child with intellectual disabilities, dealing with paperwork, forms and bureaucratic processes is often like walking into an advanced class of a foreign language with no background in that language. Families need to be freed from having to deal with this. They need to be and want to be parenting their child and focusing on that child's future."

Karen Staley
Member, PCPID Subcommittee on Family Services and Supports

The 1993 Government Performance and Results Act (GPRA) introduced the concept of performance management to federal government agencies. The Office of Management and Budget (OMB) and federal agencies are working together and asking new questions about how federal programs are performing. Are programs effective? Are they well-managed? If not, what needs to be done to improve program performance?²²

The key to providing answers regarding the degree to which programs are effective and well-managed, and what needs to be done if they are not, is the establishment of performance measures that yield valid and reliable data. Apart from simple agency performance measures, these criteria also measure both interagency collaboration and how well agencies achieve outcomes working with individuals and with organizations outside of the federal government. There are no measures requiring collaboration among related programs.

There is currently an absence of measures to assess agency support of recipient control of individual budgets to achieve new levels of personal and economic freedom. There is a need for better measures of hours worked and wages earned. There is no assessment of agency activity to partner with the private sector and to leverage resources for common valued outcomes and possible reduced dependence on government.

The Committee applauds your Performance Management Initiative, Mr. President, which has created the Program Assessment Rating Tool (PART).²³ This is an excellent approach to assessing the extent to which an agency is managing for results and maximizing program performance.

The following four sections of the PART raise a series of questions designed to provide a consistent approach to rating programs.

Purpose/relevance/federal role — to assess whether the program design and purpose are clear and defensible.

Strategic planning — to assess whether the agency sets valid annual and long-term goals for the program.

Program management — to rate agency management of the program, including financial oversight and program improvement efforts.

Program results — to rate program performance on goals reviewed in the strategic planning section and through other evaluations.

A suggested new approach for PART is to conduct an assessment *across* agencies and programs. This is necessary to determine the extent of overlapping goals and objectives and other relationships among and between agencies and programs. This would reveal the degree of an existing or total absence of a fluid continuity among agencies and programs. Continuity is very important for people with intellectual disabilities, for their disability or condition continues throughout their life span — from early family life, to education, to employment, to community living, and, finally, to retirement and end of life.

On their journey through life, is there a dam or barrier in the way, or choppy waters making their trip difficult, or do we have smooth sailing yielding a continuous flow from one step to another? Life is a continual challenge for people with intellectual disabilities. Does a particular government program contribute to making it easier for them? It may contribute to the lives of people with intellectual disabilities when it considers and fosters a continuous flow between agencies and programs rather than permits singular discrete and fragmented agencies and programs to simply exist as "satisfactory."

A singular agency or program may appear to be "successful" in accordance with PART, as currently configured, but that particular agency or program may well be a "failure" for people with intellectual disabilities. The PCPID suggests that OMB-PART consider the life span of people with intellectual disabilities when assessing agencies and programs.

The President's Committee has focused on the lack of continuity, inconsistency of objectives, and fragmentation in the performance of programs for people with intellectual disabilities. We believe that the Administration, with your leadership, has an opportunity to significantly improve the results of federal programs by utilizing the PART. With the proper performance measures in place, federal programs that have an impact on the lives of people with intellectual disabilities can be redirected from outcomes that perpetuate poverty, dependence and absence of personal freedom to valued results that lead to greater self-sufficiency, employment, and personal freedom.

It is important, Mr. President, that you encourage early application of an enriched PART that would create a new culture of measurement and accountability that raises expectations for policymakers, service providers, parents, and individuals with intellectual disabilities. A collaborative effort would develop standards, benchmarks, and indicators around consumer control of funds and the blending of resources among relevant employment, income generation and wage status, asset development and greater control of resources, and the enhanced exercise of personal freedom. Across separate federal programs, a new expectation would be created that focuses on a menu of "individualized accommodation services" that address unified learning outcomes, employment or post-secondary opportunities and savings.

These recommendations, if accepted and implemented, will reflect the Administration's commitment to achieve immediate, concrete, and measurable results. They will guide government to respond more efficiently and effectively to the demand for improved personal and economic freedom by Americans with intellectual disabilities and their families. They will help agencies identify and remove barriers to change.

Performance Management Recommendations

1. Establish a strategic partnership with the Office of Management and Budget, an appropriate non-governmental agency, and with the PCPID and other relevant federal agencies. The partnership would create a set of practical performance measures for agencies that administer federal programs that have an impact on people with intellectual disabilities to hold them accountable for the advancement of outcomes that improve personal and economic freedom. These measures and performance indicators should be comprehensive, consistent, and complementary.
2. Apply an enriched PART to 20 percent of the government's generic and disability specific programs each year, beginning in FY 2004, with follow up recommendations to address poor performance, and an annual report to Congress on the status of the improved program performance and outcomes.
3. Urge Congress to conduct at least annual oversight hearings in the House and Senate to assess cross-agency performance with the advancement of outcomes that improve personal and economic freedom for people with intellectual disabilities. Such joint hearings should extend beyond traditional lines of authority to embrace a holistic view of individual and family support that analyzes relationships among tax, finance, economic, education, health care, and workforce policies.

EDUCATION AND TRANSITION FROM SCHOOL TO WORK AND ADULT LIFE

"President Bush means No Child Left Behind quite literally. This doesn't mean that after you siphon off the children who have disabilities, or the children who were never properly taught how to read, or the children who never learned English, or the children who disrupted their classrooms, that most of the rest can learn. It means that all of our kids, even the ones our system calls "hard to teach," can learn. He understands that children with disabilities are the most likely to be left behind and have historically been left out and left behind."

The Honorable Roderick R. Paige, Ph.D.
Secretary, U.S. Department of Education

"Priorities and high expectations matter in the education of students with intellectual disabilities. Federal agencies should view services and supports for people with intellectual disabilities as a seamless pre K-16 continuum. K-12 teachers and post-secondary faculty must be trained to educate students with intellectual disabilities to meet high standards."

Annette Talis
Chair, PCPID Subcommittee on Education and
Transition from School to Work and Adult Life

Students with intellectual disabilities have made great progress in public school over the past three decades with support from their parents, educators and school officials, who are working together, working out differences and striving to meet the vision of federal special education laws. In the 21st Century, the nation can aspire to even higher expectations for people with intellectual disabilities. Public schools must now prepare students with intellectual disabilities for a meaningful place in the economy and the workforce.

In 1975, Congress passed the Education for All Handicapped Children Act (EAHCA), which was renamed the Individuals with Disabilities Education Act (IDEA) when the law was reauthorized in 1990.²⁴ This law was truly a landmark piece of legislation. Prior to that time, many children and adults with intellectual disabilities resided in large public institutions. They had virtually no opportunity to obtain an appropriate education and to prepare for employment in their own community. Those who were not routinely excluded from school had few opportunities to live full and productive lives in their own communities.

IDEA, which guarantees a free appropriate education in the least restrictive environment, ensured access to education for all students with disabilities. Students with intellectual disabilities could now participate in regular classes in their neighborhood schools and after graduation had the possibility to obtain jobs in their communities. While IDEA has played a critically important role in improving the lives of children and youth with intellectual disabilities and their families, Americans still have a very long way to go to "keep the charge."

Over the past 28 years, Congress has made improvements to IDEA. These improvements have added a preschool program; early intervention services for infants, toddlers and their families; transition services; and increased family involvement in the educational process. During the last reauthorization of IDEA in 1997, key improvements were made in including and strengthening the least restrictive environment provisions; requiring that students with disabilities have access to, participate in, and make progress in the general curriculum; and requiring that students with disabilities participate in state and local assessments, and through alternate assessments if the student is unable to participate, even with accommodations. The requirement for their participation in assessments is essential for accountability.

With the passage of the No Child Left Behind Act of 2001 (NCLB), accountability for the achievement of students with intellectual disabilities is incorporated into law. The President's Committee wishes to thank the Secretary of Education for his stance in insisting that school officials and educators are held accountable for closing the achievement gap for all students.

Critically important to achieving accountability for students with intellectual disabilities is the development of appropriate standards and assessments for them. The PCPID recommends the creation of a blue ribbon panel to develop high quality alternate achievement standards, universally designed assessment tools, and measures to assess the implementation of NCLB for students with intellectual disabilities.

This panel would function as a clearinghouse for a wide array of approaches to assessment for students being tested across the country. It would ensure that students with intellectual disabilities have access to, participate in, and make progress in the general curriculum based on standards for all students, with assessments to include all students. Stephanie Lee, Director of the U.S. Department of Education, Office of Special Education Programs (OSEP), has said:

"As we move into the 21st Century, the use of universal design principles holds great promise for all students struggling to achieve, especially students with intellectual disabilities. Universally designed and aligned standards, curriculum, instructional materials and strategies, and assessments that are designed to be valid and accessible for the widest possible range of students will provide a road map to success for students, teachers and parents."

The President's Committee is especially pleased that the Department of Education is moving rapidly to develop the National Instructional Materials Accessibility Standard,²⁵ and encourages further development of the standard to take advantage of the emerging technology, if made available, that would give students with intellectual disabilities real access to all instructional materials.

Government, school officials and educators must ensure that NCLB and IDEA work together. NCLB now gives us real accountability at the school, district and state levels for students with disabilities. This includes evaluating students' progress in reading, language arts, mathematics and science. For some students with intellectual disabilities, there should be a national and individual priority to develop reading and communication skills because a narrower focus is required to achieve success in these areas. IDEA provides the mechanisms through the Individualized Education Program (IEP) and the Individualized Family Service Plan (IFSP)²⁶ to make certain that students with intellectual disabilities, on an individual basis, make academic progress and also develop social, emotional, communication, career and vocational, self-determination skills and abilities. All of these activities should take place in inclusive environments, to the greatest extent possible, to prepare students with intellectual disabilities for both integrated employment and community living.

The Department of Education's recent efforts to work with the PCPID, scholars, parents, school officials and organizations that represent individuals with intellectual disabilities to carefully craft administrative rules (Notice of Proposed Rulemaking, Federal Register, December 9, 2003) will guide initial implementation of the NCLB provisions related to assessment and accountability for students with the most significant cognitive disabilities. The rules on assessing these students under NCLB should instruct states in developing new accountability programs. The Department of Education should review the progress of states against the following key principles:

- School districts, educators and parents should resist the tendency to prematurely presume that any child cannot meet regular achievement standards or participate in regular large-scale assessments, with or without accommodations, based on a disability or diagnosis;
- All children can be propelled with excellent instruction to achieve at higher levels over time and some students with intellectual disabilities can and should meet regular standards;
- Parents and local professionals must have the flexibility to use their own judgment, rather than mandated diagnostics such as an IQ test, to determine which learners with significant intellectual disabilities cannot meet regular achievement standards, and could not be appropriately assessed using regular standardized tests;
- The performance of some students with significant intellectual disabilities must be measured against alternate achievement standards, which differ in complexity, and that are linked to the knowledge, skills and dispositions that guide regular instruction; and

- The population of students whose learning will be measured against alternate achievement standards is finite and should not amount to more than a small percentage of the total enrollment, tethered to a flexible national benchmark of 1 percent of all students in public school.

The goal of these principles is to reverse the negative historical trend in education to underestimate the capacity of students with intellectual disabilities to learn, to view their performance as static and unchangeable and to allow the very notion of an intellectual disability to be defined by these inappropriate beliefs about potential.

Students with intellectual disabilities have made significant progress because of IDEA. The presumption of ability to work for students with intellectual disabilities should be held by all educators: both administrators and teachers. More pupils are having successful work experiences, and the President's Committee recommends that these kinds of work experiences be made available to even more students with intellectual disabilities.

This significant progress highlights the urgent need to ensure that decisions made during a student's last years of school and during the transition from school to work, be made in a way to lead to employment and income generation. While many students with disabilities are making the move to community employment, many, many more can make that transition if given necessary educational and vocational training.

If these are the expected results and outcomes, there must be periodic examination of the funding decisions made, including Medicaid funding patterns, which are developed as a result of policy for students with intellectual disabilities during the transition process to ensure that funding patterns support the outcomes we want.

The Committee believes that teachers need to provide the relevant knowledge and skills to people with intellectual disabilities that are most in need by employers. This should include specialized training for teachers in adaptive technology, which is expected to come into use more and more in classes, places of work, and a variety of other settings in the community. Of course, there are certain knowledge and skills that are basic and timeless, e.g., reading for literacy.

There is a need for a seamless arrangement of resources from all pertinent federal sources applicable to the instruction of students with intellectual disabilities. There is also a need to remove barriers that limit the use of federal resources to be pooled with state and local funds to support and to enhance learning by students with intellectual disabilities while they are in high school. This will provide them with opportunities for dual enrollment leading to post-secondary education or for entering the nation's workforce. Effective blending of funds and family involvement are essential for a successful system to serve our citizens with intellectual disabilities.

IDEA serves students through 21 years of age, depending on state law, and provides students with intellectual disabilities, ages 18-21 years, with limited options. Many of these students have had to stay in high school or participate in a "center" type program, which usually has consisted of segregated employment and earnings at below the standard minimum wage.

The President's Committee supports new emerging opportunities for students with intellectual disabilities to become involved in various transitional programs located at two year colleges or four year universities, or to participate in vocational education and training programs in integrated community-based settings. Additionally, continuing education and training should be made available to people with intellectual disabilities as it exists for other people in our society. To implement such options, there is a need for funding support from a variety of sources, such as IDEA, vocational rehabilitation, Medicaid waivers, and other appropriate sources.

Dual enrollment, a relatively new development for students with intellectual and other disabilities, allows them to complete high school while attending a two or four year college with same-age peers, pursue an academic or vocational curriculum, or a combination of both, in an inclusive setting. Such opportunity permits students with disabilities to remain eligible for services under IDEA, if deemed appropriate by the IEP.

Mr. President, in your State of the Union Address on January 20, 2004,²⁷ you announced the Jobs for the 21st Century initiative.²⁸ This initiative should include students with intellectual disabilities in all of its facets. Those facets encompass improvement in reading instructions, acquisition of reading skills, improvement in post-secondary education outcomes, and improvements in post-secondary employment opportunities for all individuals with intellectual disabilities. Grants under this initiative should be considered on a pilot basis to provide incentives to educate and serve people with intellectual disabilities. Grants should also foster community-based initiatives that lead to improved employment and post-secondary outcomes for students with intellectual disabilities.

Education and Transition from School to Work and Adult Life Recommendations

1. Develop meaningful assessments and accountability by establishing an Intra-Agency Task Force, which would be facilitated by the U.S. Department of Education and include national experts, to provide ongoing guidance to states on universally relevant standards and appropriate assessments for students with intellectual disabilities under the No Child Left Behind Act.
2. Support and promote the idea that the Jobs for the 21st Century initiative should improve reading instruction, acquisition of reading skills, improvement in post-secondary outcomes and improvement in post-secondary employment opportunities for all individuals with intellectual disabilities.
3. Develop relevant standards that apply to skills and competencies required in the work setting through a collaboration with the U.S. Departments of Education and Labor to apply the findings of the 1991 Secretary's Commission on Achieving the Necessary Skills (SCANS).²⁹
4. Support quality teacher training and professional development to help all teachers learn to elevate the achievement of all students, including students with intellectual disabilities.
5. Increase post-secondary opportunities by providing opportunities for students with intellectual disabilities.
6. Develop a seamless pre K-16 system of instruction and support to remove barriers that limit the ability of federal resources—including Social Security, Medicaid, special education, vocational education and other general education and human services resources—to be pooled with state and local funds to support students with intellectual disabilities while in high school, as they enter the workforce or post-secondary education.
7. Foster community-based initiatives, as part of the Jobs for the 21 st Century initiative, that lead to improved employment and post-secondary outcomes for students with intellectual disabilities.

EMPLOYMENT AND ASSET DEVELOPMENT

Without employment, or a means of generating income, individuals with intellectual disabilities have limited freedom.

"The theme, America Works Best When All Americans Work, emphasizes the Bush Administration's position of economic opportunity through job creation. It also builds upon the accomplishments of the President's New Freedom Initiative, which has created opportunities for persons with disabilities to be fully integrated into the 21st Century workforce."

Elaine L. Chao
Secretary, U.S. Department of Labor

"Employment generates income. Savings can provide security. Equality is the desired outcome."

Edward Mambruno
Chair, PCPID Subcommittee on Employment and Asset Development

"Every individual deserves the freedom to compete in the workplace on a level playing field, without regard to discriminatory barriers. Many individuals with intellectual disabilities are willing and able to work if provided with the right incentives and a fair chance. The federal government, in partnership with the employer community, must formulate aggressive strategies to increase opportunities for people with intellectual disabilities to seek and obtain gainful employment. Employers must recognize that individuals with intellectual disabilities represent a vast untapped pool of talent that can contribute to their bottom line productivity."

Cari M. Dominguez
Chair, U.S. Equal Employment Opportunity Commission

Employment has been, and continues to be, the central component in adult life. It is not only a pathway to economic self-sufficiency, but it is also the gateway to social inclusion for Americans. For persons with intellectual disabilities, as has been noted in prior sections of this report, there are limited opportunities to achieve a higher level of economic self-sufficiency and increased social interactions through employment. Such limitations have an impact on current levels of activity and economic self sufficiency, and foster long-term dependence upon public resources for supports and services.

Due to the unemployment rate of almost 90 percent among youth and adults with intellectual disabilities, it is clear that a social-economic safety net is needed to help to maintain and to support them and their families. This social-economic safety net must necessarily continue until the time when we have a much greater representation of people with intellectual disabilities employed in our workforce. Presently, too many people with intellectual disabilities and their families live in or near a state of poverty, or at some marginal income level. Besides the need for the continuation of the current social-economic safety net, which is absolutely necessary given our present situation, we need to open more doors to employment for youth and adults with intellectual disabilities in our society in order to reduce the unacceptably high unemployment rate.

It is time for government to adopt an economic engagement strategy for persons with intellectual disabilities. Such a strategy would recognize the interests and skills of the person and acknowledge the needs of the community, in general, to maximize the employment potential of all of its workers. Given the declining number of available workers, employers cannot afford to ignore any segment of the current and future workforce. Historically, persons with intellectual disabilities have been viewed as not able to work, and thus, considered not part of the available workforce. It is time for a change that blends the interests of persons with intellectual disabilities with the needs of the workforce and the employers in the coming decades.

Many forecasts show that there will be a shortage of available workers in the next two decades. This shortage is reflective of a number of factors, most particularly, the declining birth rate as well as the exit of the "baby boomers" from the workforce.

"There is a projected shortage of 4.8 million workers in the labor market over the next ten years. In the next 20 years, a shortage of 19.7 million workers will occur. That means that employers are going to have to look differently at whom and how they hire."

Armentha Cruise
President, Aspen Group

Similar findings have been noted by a number of labor economists. The challenge is to make sure that the native abilities and skills of persons with intellectual disabilities do not go unrecognized. The interests and skills of this untapped labor pool can play a significant role in responding to the critical labor shortages forecast in the coming years. Improved educational experience and the aging of America will create new opportunities for persons with disabilities in the workplace. As a result, a new set of relationships must be forged with employers and the business community that transcends past perceptions and attitudinal barriers.

Persons with intellectual disabilities can work, and want to work. Research has shown that for many of these persons, there is a perception that employment is not a realistic option. The internalized belief that one cannot work is well founded in the current policies and practices that require persons with disabilities to document inability to work as a pathway to accessing financial and health benefits.

The presumption of an interest and ability to work by people with intellectual disabilities needs to exist among all educators and prospective employers. For this reason, meaningful work experience needs to be provided at both the secondary and post-secondary school level for the benefit of youth and young adults who are preparing for employment. This work experience should coincide with the needs of the open job market. Employers need to recruit workers with readily usable work experience.

There is also a need for public awareness programs to educate and to stimulate prospective employers on the capabilities of individuals with intellectual disabilities. The work experience opportunity, coupled with a positive and receptive attitude among prospective employers, should help lead to the reduction of the very high unacceptable unemployment rate among people with intellectual disabilities. Meaningful work experience should result in more employment opportunities and the generation of both income and savings for our citizens with intellectual disabilities, which are largely non-existent at the present time.

It is important to recognize that there is a need for open competitive and integrated employment for people with intellectual disabilities, where they can earn at least the standard minimum wage or higher. Many individuals with intellectual disabilities are currently employed in work centers that are not integrated and that pay less than the standard minimum wage. In 2002, 24 percent of vocational and day program participants in the United States worked in supported or competitive employment while the remaining 76 percent of participants received services in segregated settings, including sheltered employment, day activity, and day habilitation programs.³⁰ As more and more students with disabilities complete effective employment transition programs in school programs, their potential will increase and, we hope, their horizons will improve. We need to promote the concept that youth and adults with intellectual disabilities are not only interested in and able to work, but should be employed in fully integrated settings at or above the standard minimum wage. For a society that fosters democracy, this makes good sense.

If these are the expected outcomes, then we need to conduct periodic examinations of our funding decisions and patterns, including Medicaid funding patterns, which lead to vocational training, work experience and transition into employment for people with intellectual disabilities in the American workforce. There are funding patterns that continue to exist, which tend to limit the employment opportunities of people with intellectual disabilities. These funds are often not blended for maximum effectiveness and efficiency.

Many of the funding patterns are archaic, based on myths and faulty beliefs about people with intellectual disabilities that existed many decades or centuries ago. People with intellectual disabilities are full citizens in our nation and are deserving of truly proper and acceptable treatment as Americans living in a modern civilized society. The funding decisions and patterns for education, transition, rehabilitation and employment need to be evaluated and improved for the benefit of our citizens with intellectual disabilities.

When considering the changing demographics of the general workforce, it is apparent that the economy will need available workers. Employment for persons with intellectual disabilities is sound practice and must be supported by clear policies at the local, state and federal levels that encourage work for all. For persons with intellectual disabilities, the benefits of entering the labor market are clear for the individual as well as for the economy.

What is not apparent is that when persons with intellectual disabilities enter employment, they often free up an additional worker — the family member who has served as caregiver. For family caregivers, the indirect benefit to employment of their disabled family member is their own increased family income, expanded personal networks, and increased self worth and value in the marketplace.

Not only from a public policy perspective, but also from an advocacy perspective, employment allows a person to participate in community activities and create options for long-term financial stability through increased savings. Without a means of generating income, individuals with intellectual disabilities have limited freedom. A long-standing challenge is to develop interests and skills early in the educational experience of students with intellectual disabilities. Experiential learning has been shown to be an effective educational strategy for all students.

The successes of the school to work activities have shown that all students can learn by doing. For students with intellectual disabilities, there is a clear indication that if employment is viewed as an option early, the likelihood of entering the workforce is considerably greater.

""Numerous studies have documented that if a person with an intellectual disability has a work experience in high school, he or she is much more likely to be working five years after leaving school than those who do not."

William Kiernan
Director, Institute for Community Inclusion

Lest there be any doubt about a ready and willing to work perspective, one only has to ask a person with a disability what their perspective is about work. Michael Rogers, a self-advocate and member of the PCPID Subcommittee on Assistive Technology and Information, noted:

"We have to change the beliefs of people with disabilities that they cannot work. There are very few of us who actually do work. If you hang around people who say you can't do anything, guess what? You can't do anything]"

The same sentiment expressed by Michael Rogers has been reported numerous times by the National Council on Disability (NCD) through their Harris Poll surveys on employment of persons with disabilities. There is an interest and commitment to work, but at times not a clear policy or practice path into the general labor force. Students with intellectual disabilities who are exiting school should transition to employment. For the more than 1.2 million persons with disabilities served in day and employment services nationally, the considerable strength of this untapped labor force remains an opportunity for employers. Persons with intellectual disabilities can, and must, be part of an economic engagement strategy that responds to our labor shortages in the coming years.

Another significant barrier to integration in the wider community is lack of control of resources. People with intellectual disabilities and their families need control of the resources they receive from public agencies (and upon which they depend) to address fundamental issues of housing, transportation, technology and the production of private income and savings. Given the strong movement for increased consumer direction and greater economic self-sufficiency, employment, increased earnings, and capacity to develop longer term ways of supporting one's self through personal savings are all part of the future for persons with intellectual disabilities.

Most adults with intellectual disabilities are capable and interested in working and earning an income and would like to save some of their earnings. However, only a small number of adults with intellectual disabilities are currently employed. Of this group, most are employed only part-time or temporarily, and many earn wages that are lower than the nation's minimum wage. As a consequence, they are unable to generate sufficient income to open a savings account. Persons who are poor can be made even poorer by the continuing threat of government taking away benefits before they have a chance to succeed.

Thus, there is a need to maintain and improve the existing social-economic safety net, which Americans with intellectual disabilities and their families can grasp and hold on to in order to survive from day-to-day. The current social safety net must continue. Understandably, adults with intellectual disabilities need to gain full employment to achieve a satisfactory sense of security. They also justifiably seek the opportunity to build assets to an adequate level. The desires of persons with intellectual disabilities are like those of any American citizen. Given the social-economic safety net, plus a solid chance to succeed, such individuals and their families will be able to survive and, hopefully, contribute to America in many ways in the future.

As is the case for those without disabilities, long-term financial planning strategies for persons with intellectual disabilities are crucial. Financial stability, as one gets older, often requires early planning and creating assets that will allow for some degree of independence from public supports in later years. Planning for retirement for the general population has resulted in a variety of products and mechanisms available for personal investment. This has also been extended to parents wanting to save for their children's college education. Providing opportunities for similar long range financial planning for people with intellectual disabilities is becoming more essential.

The interest from a public policy perspective is the development of programs that reduce dependence on public assistance now and in the future. The development of strategies that will allow persons with intellectual disabilities who are economically disadvantaged to set aside assets for future use, while preserving those services and supports that are essential now, is a shared concern. If we do not provide some creative options for families, the difficulty of public funding to meet the growing needs of this population is likely to become a serious problem in the future. The need for more effective integration of services, supports and resources is apparent.

At the federal level, initiatives must allow for the blending of resources; at the state level, agencies must consider how mandates for comprehensive services leading to employment are structured; and at the local level, resources must be brought to the table so that persons with intellectual disabilities can enter and remain in employment. It is evident that:

"To create a new system will require a re-design that relies on the creation of new tools and structures. They [tools and structures] include fiscal intermediaries, where a blended and targeted amount of dollars is deposited and assistance provided in complying with all applicable federal and state laws, as well as reporting requirements; independent assistance that is conflict of interest-free to help with planning and implementation; and, finally, creative and personal individual budgets that accurately reflect and help purchase hopes and ambitions for achieving the American dream that individuals with disabilities possess."

Thomas Nemey
President, Center for Self-Determination

One exciting new development based on the waiver authority of the Social Security Administration (SSA) was announced in the Federal Register on February 5, 2004. It will allow individuals who enter employment to set aside some of their earnings in a savings account. In these instances, the individual will be able to retain earnings, gradually reduce cash benefits, and preserve some of these earnings in an asset development account as a form of support in retirement years. For the Centers for Medicare and Medicaid Services (CMS), the development of comprehensive employment options, as presented under their Medicaid Infrastructure Grants, will allow continued access to health care until the individual is able to secure such benefits through the workplace.

Flexibility in the use of the waivers will allow states to design a system that recognizes the economic environment in the state, the general labor force needs and the support of the individual with intellectual disabilities when entering employment. The dual waiver would be managed collaboratively, but streamlined in the application and approval process by both CMS and SSA.³¹ The dual waiver holds great promise for improving community-based services for people with intellectual disabilities and should be promoted nationwide.

In addition to the dual waiver, it is equally important to create a "Qualified Disability Savings Account" (QDSA) that would provide incentives for individuals with intellectual disabilities, and their families, to participate in long-term planning and savings. The QDSA would offer a savings plan with tax deferred earnings and not count as an asset in determining eligibility for SSI and Medicaid. The funds could be used to supplement, not supplant, government benefits for access to technology, transportation, health care, and continuing education and training. Similar to a "529 plan"—a college tuition savings plan—the QDSA would provide tax deferrals on the income from the account and income tax disregards that would help families with children with intellectual disabilities respond to lifetime needs for services and support.

Experts have advised us that there is presently no vehicle that educates and encourages families to do long range planning and saving specifically for services for someone with disabilities. The Qualified Disability Savings Account would provide such an incentive, with money targeted specifically for use by the person with disabilities, which would not exclude them from government benefits and services. Another unique aspect to this account is that the distributions can be made only to third parties for payment of services or products that are for the sole benefit of the qualified beneficiary.

The PCPID urges the use of an Individual Development Account-like instrument to encourage savings by persons with intellectual disabilities. In 1998, the Assets for Independence Act was passed to encourage asset accumulation and self-sufficiency for low-income families. These trust or custodial accounts were specifically designed for the purchase of a first home, college savings, or starting a business. Individual Development Accounts (IDAs) are comprised of the participant's savings from earned income, and are matched by deposits of up to eight dollars for each dollar saved.³² The goal was to encourage the participants to develop strong habits for saving money.

Persons with intellectual disabilities have not historically used IDAs because of the fear of losing their benefits. Building on the dual waiver recommendation, the IDA-like instrument would offer an opportunity for people with intellectual disabilities to save for personal choices, based upon their own needs. These would include, for example, the purchase of assistive technology tools for uses that are personal or recreational in nature.

Any action plan to promote and support asset development for persons with intellectual disabilities will require the following:

- More flexibility in federal regulations regarding countable assets in both eligibility determination and continuation of service delivery.
- Recognition of the need to have long-term plans for asset development, thereby creating opportunities for shared resource allocation in later years (individual and public partnership).
- Establishing new ways of linking federal resources at the state and local levels to address issues of increased employment options through modification in regulations and rules governing use of funding and eligibility determination through special waivers, model demonstrations, systems change and flexible financing.

America applauds the efforts of the Administration to swiftly implement the recommended list of actions for employment of people with disabilities outlined in the New Freedom Initiative. We realize that what relates to people with disabilities includes individuals with intellectual disabilities. The New Freedom Initiative includes numerous actions, including the following:

"The full enforcement of the Americans with Disabilities Act, promoting understanding and use of tax incentives to promote the hiring of people with disabilities, promoting best practices to enhance employment opportunities for people with disabilities, promoting the federal government as a model employer of people with disabilities, reaching out to people with disabilities who have never had the opportunity to work before, reducing the unacceptably high rate of unemployment among people with disabilities, and other areas pertaining to employment of people with disabilities."

These actions are also of enormous significance to citizens with intellectual disabilities and their families.

Employment and Asset Development Recommendations

1. Authorize a streamlined process and accelerated timetable for states to secure approval of a dual waiver through the Social Security Administration and the Centers for Medicare and Medicaid Services that provide incentives to work, and accumulate assets for individuals with intellectual disabilities without losing their eligibility for benefits.
2. Propose the establishment of Qualified Disability Savings Accounts (QDSAs) to encourage individuals with intellectual disabilities and their families to participate in long-term planning and savings, which will advance personal and economic freedom. Moreover, a QDSA would not exclude a person from receiving government benefits.
3. Explore the structure of current Individual Development Accounts (IDAs) to determine whether they would require modification for qualified persons with intellectual disabilities to use as a savings account. Expand the opportunities to save for purposes based upon an individual's own needs without losing benefits.
4. Establish a strategic partnership with the U.S. Departments of Labor, Education, Transportation and Commerce, the Centers for Medicare and Medicaid Services, the Social Security Administration, the Equal Employment Opportunity Commission and the Small Business Administration to promote employment of people with intellectual disabilities. In concert with the PCPID, these eight federal agencies have the expertise and experience to leverage current employer relationships to stimulate new investment and support of individuals with intellectual disabilities in the workplace. An appropriate agency, like the Department of Commerce or Labor, should assume the leadership role in convening five forums concerned with employment of people with intellectual disabilities.

Forum 1: Convene a forum of small business leaders to promote a better understanding of the strengths of people with intellectual disabilities as employees and to discuss and resolve current issues concerned with employment of people with intellectual disabilities in small business establishments.

Forum 2: Convene a forum of large business leaders to promote a better understanding of the strengths of people with intellectual disabilities as employees and to discuss and resolve current issues concerned with employment of people with intellectual disabilities in large business establishments.

Forum 3: Convene a forum of human resources leaders to discuss and resolve current issues concerned with employment of people with intellectual disabilities, including appropriate announcements for jobs, appropriate application forms for employment, appropriate techniques for recruitment and selection of employees, appropriate pre-employment education and on-the-job training opportunities for improvement of performance by employees with intellectual disabilities, and other areas as may be identified.

Forum 4: Convene a forum on network capacity building, at the local level, with voluntary organizations for developing knowledge and skills for individuals and families on how to enter the job market and develop desirable personal contacts and supports.

Forum 5: Convene a forum of leaders from the transportation industry, advocacy organizations for people with intellectual disabilities, rehabilitation service organizations and federal agencies to develop initiatives targeted at improved access to transportation systems by people with intellectual disabilities. Access to transportation is pivotal to the employment, medical and health care, and education of people with intellectual disabilities.

FAMILY SERVICES AND SUPPORTS

"With his New Freedom Initiative, President Bush has placed a special priority on removing the barriers that face people with disabilities. Long-term commitment to this goal is essential because the barriers that stand in the way of equal access are deep-rooted. They can be found throughout our health care, transportation, housing and education systems and elsewhere."

"At HHS, we have a special responsibility to help remove barriers to community integration. Too often, people with disabilities have been forced to live in institutions, many times because the services that would enable them to live in their communities are not available. We need to help provide for those services, and at the same time, we need to support the many informal caregivers, the family and friends of people with disabilities, who dedicate themselves to providing the informal help with routine daily life in the community."

Tommy G. Thompson Secretary, U.S. Department of Health
and Human Services

"I believe today, as I believed over a decade ago, as a co-author of the Americans with Disabilities Act, that accessibility in transportation is a civil right."

Norman Mineta Secretary, U.S. Department
of Transportation

"For beneficiaries who leave the SSI rolls, many of whom are persons with intellectual disabilities, only 0.2 of one percent leave the rolls voluntarily."

Martin H. Gerry
Deputy Commissioner, Disability and Income Security Programs
Social Security Administration

"Our focus has been on looking across the life span at solutions to improve the quality of life for people with intellectual disabilities and their families. Families of children with disabilities need supportive options to access quality health and mental health care. Perpetual poverty and hopelessness should not be a prerequisite."

Brenda A. Leath
Chair, PCPID Subcommittee on Family Services and Supports

Too often, it is the standard, rather than the exception, for families of people with intellectual disabilities to have to navigate an uncharted course across multiple systems to access needed services. Armed with only limited information, most of these families face a myriad of obstacles and barriers. They endure long waiting lists for services, must decipher and respond to conflicting program eligibility requirements, and wade through substandard care experiences to find scarce quality health and mental health care.

They have also persisted in seeking suitable and dependable respite care, self advocated for meaningful educational and employment experiences, and demanded their rights to safe and affordable housing and community integration. Stigma and discrimination exacerbate the indignities felt by these individuals and families, perhaps more so by those enmeshed in poverty. Changing this paradigm for families requires far greater collaboration, integration, coordination, and accountability at all levels of decision-making and service delivery. We must address the "personal" needs of the individual with an intellectual disability as well as the "collective" needs of the family. The Committee has identified three critical areas that will help to chart a new course for families: personal health and mental health care, respite care for families and caregivers, and access to safe and affordable housing.

Personal health and wellness is essential for achieving and sustaining quality of life. The Surgeon General's Report, Closing the Gap, released in 2002,³³ identifies multiple challenges that impact the quality of life for people with intellectual disabilities. Despite the fact that people with intellectual disabilities live longer, their life span still is shorter than the average person. Among the vast array of contributing factors cited for these health disparities are a shortage of adequately trained health professionals to care for persons with intellectual disabilities and disincentives in Medicare, Medicaid, and third party payer reimbursements.

Mr. President, there should be equal access to quality care by all who need it. Efforts to overcome these challenges will require construction of a more responsive system of care that begins with improved attitudes and up-to-date information. Also important to a more responsive system of care is appropriate training of health professionals to manage the medical, psychiatric and dental health needs of children and adults with intellectual disabilities.

Other critical steps must focus on the elimination of financial and non-financial disincentives. Attention must be given to the observations of self-advocates and their families that too often some providers shy away from including people with intellectual disabilities in medical and dental practices. Such claims need to be examined and resolved. As these issues are addressed, emphasis must be placed on decreasing the incidence of preventable causes of intellectual disability before and after birth through prevention, early detection, and treatment.

We must also relieve restrictions for maintaining Medicaid eligibility for persons with disabilities when family members work. Under current laws, families of persons with disabilities who need Medicaid support also must comply with household income and asset caps in order for their child to continue receiving Medicaid. This requirement prevents a mother, father, and siblings from earning adequate wages and saving any portion of their earnings. Essentially, they are being penalized for protecting their child's (or family member's) Medicaid eligibility and coverage.

Providing adequate supports to the family is critical. Respite care is the most frequently requested family support service. It provides occasional relief to families who care for loved ones with intellectual disabilities. For these families, care giving is often a lifelong responsibility. A University of Colorado³⁴ study determined that:

- 2.79 million of the 4.56 million people with developmental disabilities in the United States in 2002, many of whom were persons with intellectual disabilities, were receiving residential care from family members.
- Of that group, 25 percent lived with family caregivers older than 60 years.

Another report indicated that 71,922 persons with developmental disabilities were on formal state waiting lists for residential services in 2000.³⁵

Although respite care has been shown to help sustain family stability, improve family caregiver health and well-being, and avoid out-of-home placements, it remains in critical short supply in most states. This is due, in part, to a lack of qualified, trained providers and limited resources, eligibility requirements, geographic barriers, cost, and a lack of culturally sensitive programs.

The result has been the perpetuation of an unresponsive, duplicative, and fragmented system that families often find impossible to navigate. Viable solutions require coordinated systems and blended funding streams for families across the life span. Such an approach, nationally, would facilitate easy access to an array of affordable, quality respite services for families of people with intellectual disabilities.

Americans have the right to safe and affordable housing. The need to develop diverse independent living options and opportunities will become increasingly critical as caregivers and people with intellectual disabilities age *and* caregivers reach the ends of their lives.

Housing programs will need to develop new rental and purchase options that provide people with intellectual disabilities with opportunities to transition into the community. Such programs will need to balance eligibility criteria and juxtapose them against other programs that offer support to this population.

In preparation for the increased need and demand for adult independent living arrangements, community-based demonstration initiatives should be considered a viable option for developing housing models that offer supportive living environments. Such programs should also incorporate independent living training activities. Home and community-based waivers should be considered as one of several mechanisms to support program designs.

Improving the quality of life for people with intellectual disabilities requires a focus on the personal and collective needs of individuals and families, as well as coordination and provision of comprehensive support services that respond to individualized needs. Families must be provided with culturally competent, age- and gender-specific support, based on time-sensitive assessment of psychological, medical, social, and behavioral needs.

The Committee is aware of and pleased with the efforts of the Administration to swiftly implement the Olmstead Decision. In addition, as part of the New Freedom Initiative, the Administration has proposed a \$ 1.75 billion initiative through 2009 (the "Money Follows the Individual" Rebalancing Initiative), and is seeking to promote home ownership and expand rental housing options. But, there is no single solution or simple answer. Access to quality health and mental health care, respite care, and affordable housing requires state and federal commitments and investments that cut across agency boundaries and professional disciplines.

A multi-faceted and system-wide transformation process is needed. This process, as previously stated in the Section entitled "Employment and Asset Development," should:

- Meld multiple waivers, including SSI and Medicaid, into one seamless set of incentives for work and self-employment, safe and affordable housing, and control over transportation.
- Assess the impact of waiver bundling on such issues as individual choice, access to community-based and family support services, affordable housing, transportation, access to health care and needed technology, and earned income and asset accumulation through the use of state demonstration projects.

Employ a special public-private partnership initiative as a vehicle to enhance the pre-service and in-service training of physicians, dentists and other health care professionals to provide care to people with intellectual disabilities in community settings. This partnership should comprise various federal agencies and the leadership of major health professions associations and advocacy organizations. It should include physician incentive options for expanding patient panels to include people with intellectual disabilities and to establish provider recognition and awards for exemplary performance in medical and health care management of people with intellectual disabilities.

Allocate funding to support focused research designed to achieve parity in health care for persons with intellectual disabilities. Such research should examine provider attitudes, behaviors, practice patterns, specific reimbursement barriers, and new financing proposals.

Provide adequate resources for demonstration initiatives designed to assess the efficacy of respite care service approaches that include faith-based, community-based, and employer-based options.

Family Services and Supports Recommendations

1. Authorize a streamlined process and accelerated timetable for states to secure approval of a dual waiver through the Social Security Administration and the Centers for Medicare and Medicaid Services that provide incentives to work and accumulate assets for people with intellectual disabilities without losing their eligibility for benefits. This recommendation is repeated because it was developed by both the Subcommittee on Family Services and Supports and the Subcommittee on Employment and Asset Development.
2. Establish an Interagency Task Force on Developmental Health that is facilitated by the Centers for Disease Control and Prevention with the PCPID, and includes representatives from the Centers for Medicare and Medicaid Services, the Administration on Developmental Disabilities, the Bureau of Health Professions, the Agency for Health Research and Quality, and private sector organizations.
3. Commission longitudinal studies to: 1) design new financing options and assess their impact on service access and delivery to persons with intellectual disabilities, and 2) examine provider attitudes, behaviors relative to inclusion of persons with intellectual disabilities in community-based and private practice settings.
4. Relieve restrictions for meeting Medicaid eligibility for persons with disabilities when family members work by raising the income threshold for Medicaid eligibility.
5. Convene a "White House Conference on Respite Care" to identify model service approaches that benefit families with members with intellectual disabilities.
6. Conduct housing demonstration projects that include support services for adults transitioning from in-home dependent care to independent living environments. Encourage the Department of Housing and Urban Development and the Centers for Medicare and Medicaid Services to collaborate with states to test affordable and accessible community housing models that promote independence and offer supportive services when needed.
7. Support and promote respect for the civil rights, liberties and dignities of people with intellectual disabilities, which need to be respected in the environment of anti-terrorism tactics and strategies as developed and practiced by the Department of Homeland Security and related agencies.

ASSISTIVE TECHNOLOGY AND INFORMATION

"New technologies are opening opportunities for work, community living, and independence for those with even the most severe disabilities. The New Freedom Initiative commitments will help jump start research in assistive and universally designed technologies and will help ensure that Americans with disabilities have access to those technologies."

New Freedom Initiative
2002

"Technology helps level the playing field for persons with intellectual disabilities at home, at school and in the workplace."

Claudia Coleman
Chair, PCPID Subcommittee on Assistive Technology and Information

People with intellectual disabilities substantially lag behind all other groups in our society in the utilization of technology. Technology is a critical means to enhance productivity, maintain independence, and expand quality of life choices. For people with intellectual disabilities, technology can be the critical difference between living at home and nursing home care, unemployment and work opportunity with advancement potential, freedom to move about independently and dependence on caregivers for direction. In the near future, exciting developments, such as improved voice recognition systems with one-word commands for performing many tasks, and advances in software development permitting creation of assistive devices to adapt simultaneously to the learner's personal cognitive style and to the learner's environment, are likely.

These and other fundamental advances in micro-electronics, wireless technology, and software development have the potential to significantly reduce income maintenance and long-term care costs to government at the federal and state level, as well as lower out-of-pocket expenses for individuals and families. There are unique challenges, such as volume, scale and cost, that must be overcome if persons with intellectual disabilities are going to have access to assistive technology.

A strong federal role is critically needed to address these challenges and to stimulate the development of strong partnerships between technology companies, research universities, and consumers with intellectual disabilities and their families and service providers. Federal leadership is needed to stimulate research, development, commercialization, and dissemination of cognitive technologies for people with intellectual disabilities in the home, at school, in the workplace, and to promote health and well-being.

The Committee applauds the focus on assistive technology in the New Freedom Initiative. It seeks to speed new technologies to individuals with disabilities, expand the U.S. assistive technology industry, and boost exports of U.S. products and services. Already, the Department of Commerce is working with the Assistive Technology Industry Association (ATIA), industry trade associations, and disability organizations to provide data analysis to increase export promotion opportunities, provide technical manufacturing guidance, and catalog trade barriers.

Other activities in which the Department of Commerce is engaged include reaching out to industry through forums and roundtables to encourage sharing of manufacturing information among industry and trade associations; facilitating the development of measurement and private sector standards for assistive technology devices; and raising awareness of sources of technical assistance, product ideas and patented inventions.

The President's Committee also believes that all of these activities should include a focus on assistive technology for persons with intellectual disabilities, and that this inclusion should take place in a systematic and comprehensive manner. The Committee believes it is important to create a network of research centers of excellence in technology and intellectual disabilities.

- The Centers would be located in multidisciplinary, university-based settings and closely linked functionally to commercial enterprises in technology.
- Core disciplines would include computer science, electrical, computer, and biomedical engineering, psychology, rehabilitation, and special education.
- Centers would engage with consumers with intellectual disabilities, their families, service providers, employers and schools to facilitate the development and dissemination of viable new technologies designed to increase the social, economic, and educational participation of people with intellectual disabilities. Centers would also promote the development of financing strategies to increase access and use of current and new technologies.

The following agencies would need to closely cooperate to develop these centers: the Department of Commerce, including its Technology Laboratory; the Department of Education, including the National Institute on Disability and Rehabilitation Research (NIDRR) and the Office of Special Education Programs; the Department of Health and Human Services, including the Administration on Developmental Disabilities (ADD) and the National Institute of Child Health and Human Development (NICHD), which is a part of the National Institutes of Health (NIH); the Department of Labor and the Department of Transportation.

These centers would seek to stimulate the resources and expertise and the crucial participation, currently lacking, among relevant engineering and computer science faculties in institutions of higher education. The centers would emphasize and facilitate interaction between the commercial technology industry and these faculties in developing new products, devices, and technologies for people with intellectual disabilities. This, in turn, would stimulate technology development and reduce the rapidly growing "digital divide" in our country.

Advances in technology are already beginning to make a difference in the lives of people with intellectual disabilities. In 1997, AbleLink Technologies, located in Colorado Springs, received a call from a Colorado School District's transition office. Steve, a student-employee with an intellectual disability, was having problems with his warehouse job at a Target store. He had difficulty remembering the things he had to do, and was afraid he would lose his job. The transition job coach provided Steve with a Pocket Coach, recorded instructions for the eight different tasks required for the warehouse position, and set the Pocket Coach to play back an audio and visual "to do" list. In three weeks, Steve was able to repeat verbatim each of the eight task instructions, and said that he did not need his Pocket Coach any more. The store also gave Steve his first raise. AbleLink's "Pocket Coach" is a personal assistant with a software program that runs on the Windows operating system. The Pocket Coach provides an easy-to-use interface for recording and retrieving a series of step-by-step audio and video instructions guiding individuals at their jobs, in performing activities of daily living, or in prompting for other tasks. (Information on AbleLink's Pocket Coach is available at: <http://www.ablelinktech.com/>)



1. **Assistive Technology and Information Recommendations**

2. | Support the establishment of a network of "Research Centers of Excellence in Technology and Intellectual Disabilities" to engage in research and development on new technologies to improve the quality of life, wellness, and independent living of people with intellectual disabilities.

3. | Encourage White House leadership to convene a meeting of relevant agencies, including the Departments of Labor, Education, Transportation, Commerce and the Equal Employment Opportunity Commission, to promote access to technology which advances the employment opportunities of people with intellectual disabilities.

- Convene a forum, coordinated by the PCPID, to identify new and improved strategies to stimulate manufacturers' investment in design and development of products that advance independence and the productivity of people with intellectual disabilities. The PCPID urges that a major emphasis be placed on the creation of a common architecture in the development of assistive technology. In addition, emphasis should be placed on the creation of synergy between government funding and assistive technology access and use in the home, workplace, and community.
4. |

Encourage the Departments of Education and Labor to fund a series of demonstration projects that emphasize public and private sector coordination and investment.

Road Map to Success

There is no single path to freedom. Despite multiple challenges, the following three individual stories of perseverance describe what is possible for still too few Americans with intellectual disabilities.

The recommendations of the members of the PCPID provide a clear voice and vision for change in our policies and practices. These recommendations serve as a road map to guide individuals, families, communities and government to create the path to personal and economic freedom. Opportunities to earn income and grow assets will fundamentally alter access to affordable housing, health care and education.

Transition from School to Employment A Success Story



Maclaen Bumingham, 19 years old, graduated from high school in 2002. He lives with his family in a rural town in Montana. Like many students in Montana who receive special education services, Maclaen did not have the option to attend school past age 18. Fortunately, his principal believed that part of his education should be community-based and lead toward employment. During his junior and senior years, Maclaen had a variety of work experiences. Through these experiences, Maclaen, his family and his Individual Education Plan (IEP) team learned more about his skills and the supports and training he would need to maintain employment. The team's goal was to place Maclaen into a long-term, paid job before graduation and to develop a coordinated plan to maintain employment.

Since Maclaen did not have access to many supports and services after school, developing a solid job for him was critical. While Maclaen was eligible for Developmental Disabilities services, there was a long waiting list for both supported employment and supported living services (he was offered a place in a community rehabilitation program, but the family declined). Vocational Rehabilitation provided some time-limited funding, which did help the school with job development. His only long-term supports, then, were his family and Social Security Administration (SS A) work incentives. Maclaen's team knew that if he was working when he graduated, he would be eligible for an SSA Plan for Achieving Self-Support (PASS). The PASS would serve as the primary funding source to purchase follow-along supports critical to his continued success in employment.

Since graduation, Maclaen has been employed in a combination of jobs with hourly wage ranges from \$5.15-\$6.00. To provide his follow-along supports, he hired his retired special education teacher. His family transports Maclaen to work since he doesn't drive and there is no public transit. His current vocational goal is to pursue a career as a literacy tutor. In addition to paying for his follow-along services and transit, the PASS will fund tutoring to enable him to increase his literacy skills.

Today, Maclaen tutors students for the school district. He recently received an award for his services and the local newspaper featured his work. He also has part-time employment at both the auto glass store and the public library. He works an average of 15 hours/week, but has a goal of working full-time. His mom monitors his PASS and serves as his mentor. She negotiated his current job that allowed him to move from janitorial duties to a Literacy Coach position. Maclaen directs his follow-along supports by asking for assistance when needed.

Self Employment A Success Story



Michael McHugh, 38 years old, has a moderate intellectual disability. At three years of age, he was in a car accident that led to cerebral palsy. He struggles with a stiff, unsteady gait and leans on a walker to accomplish all tasks. He has no reading or math skills, and because he has delayed speech, it takes a lot of effort for a stranger to understand him. Michael attended special education classes, and prior to starting his own vending machine business, he worked at a community rehabilitation program. He receives Social Security Disability Insurance (SSDI) and very recently received some Vocational Rehabilitation funding support.

Michael lives with his mother in a rural area in southwest Michigan. Now in his third year of business, Michael J's Vending presently operates seven pop machines and two snack machines at six locations with strong potential for four more machines at two additional locations. Michael hired an assistant through his individual service budget by utilizing a fiscal intermediary. His employee transports him and assists with positioning products so that Michael can fill all of the machines. In addition, Michael sorts coins and makes his bank deposits, purchases snacks at an outlet, and greatly enjoys his business lunches at his favorite restaurants. Michael projected an average monthly income in 2003 of more than \$200.00, significantly greater than the average of \$5.00 per month working at the community rehabilitation program.

Self-employment seems to fit Michael's needs because both he and his mother wanted to maintain an active lifestyle not tied to a schedule or routine, as was offered by the community rehabilitation program. A trusting relationship with an Allegan County Community Mental Health (ACCMH) Social Security benefits specialist provided the foundation that led to further confidence building by Michael and his mother.

During the summer of 2000, ACCMH staff helped develop a business and marketing plan with three-year projections. Consulting work with Griffin-Hammis Associates provided expertise in both business planning and the approval of a \$14,000.00 PASS with the PASS Cadre office. Michael's PASS allowed him to purchase a van with a modified ramp. ACCMH assisted Michael in utilizing a fiscal intermediary to hire his own staff, and through funding support from Vocational Rehabilitation, he purchased two used vending machines to expand his business. His coordination and strength have increased and Michael has also grown significantly in his confidence and sense of self-worth. He now chooses to close his own door, buckle his own seatbelt, and be involved in family conversations, and has been a paid co-presenter at six state conferences.

In 2002, Michael paid over \$550.00 in sales taxes and purchased over \$10,000.00 in inventory to contribute to the state and local economy. Michael has been able to surmount community barriers and become a participating and respected community member. He strives to live and work without SSDI monthly payments. The learning curve gained from supporting Michael has allowed ACCMH to assist five more people with intellectual disabilities to become business owners.

Toward Personal and Economic Freedom A Success Story



Mia Peterson, 29 years old, has Down syndrome and exemplifies leadership and excellence. She grew up in Webster City, Iowa, with her family and graduated from Webster City High School in 1993. During high school, Mia was involved in cross-country running, theater and speech competition. Mia currently lives independently in an apartment in Ohio. She works at the Down Syndrome Association as the self-advocacy coordinator. She is also self-employed as a national co-facilitator of Stephen Covey's "Seven Habits of Highly Effective People." With her business, Aiming High, she speaks to groups across the country and sells her musical CD entitled, "I Am Here." Mia has lived in Ohio since 1997 when she started working for Capabilities Unlimited, Inc., as a co-editor and columnist for the *Community Advocacy Press*, a newsletter by and for people with intellectual disabilities. Mia has also taken courses at Xavier College to develop her communication skills and explore her career interests.

Mia's professional interests and passion for self-advocacy extend to her many community activities and leadership positions. She currently serves on the National Down Syndrome Society's board of directors and chairs the organization's self-advocate advisory board; serves as a board member of her local YMCA; and on numerous local and state committees. She served as the first president of People First Ohio, on the National Youth Leadership Council, and as a board member for the Association of Persons for Supported Employment. In 2001, Mia became the first individual with Down syndrome to testify before a U.S. Senate committee regarding the impact of the ADA on her life. She partnered with Joan Medlen, a registered dietitian, to conduct a research study on nutrition for people with Down syndrome and received the National Down Syndrome Society Research Award for her contributions. Mia also enjoys running, swimming, bicycling, participating in church activities, corresponding with family and friends, and spending time with her boyfriend. Recently, she ran the five-mile leg of a marathon and carried the Olympic torch through Cincinnati in the 2002 Winter Olympics.

We applaud the three success stories of our citizens with intellectual disabilities. They are wonderful examples of what can happen when individuals with intellectual disabilities are given the opportunity to succeed. However, we must not be misled by these three success stories into thinking that they are typically representative of people with intellectual disabilities, for they are not. Far too many Americans with intellectual disabilities are not even given the opportunities necessary to succeed. It is well to remember that faulty attitudes and erroneous myths continue to exist about people with intellectual disabilities. This is demonstrated by the fact that almost all citizens with intellectual disabilities currently are unemployed in our free and civilized nation.

These success stories remind us of the possibilities that can exist for our citizens with intellectual disabilities. This report provides us with examples of important ways to open doors that will lead to their success and full citizenship. Mr. President, we ask for your help in this matter.

Executive Summary and Recommendations

"Government likes to begin things - to declare grand new programs and causes and national objectives. But good beginnings are not the measure of success in government or in any other pursuit. What matters in the end is completion. Performance. Results. Not just making promises, but making good on promises. In my Administration, that will be the standard from the farthest regional office of government to the highest office of the land."

George W. Bush
Governor of Texas
June 9, 2000

The core ideas of the President's Committee for People with Intellectual Disabilities have grown out of one overarching conclusion. We have concluded that, historically, public assistance in exchange for enforced poverty and the absence of freedom is a bad deal - one that fails all parties to the arrangement: people with intellectual disabilities, their families and the American people. A great challenge before our government and society is to *will* a public safety net that not only permits persons with intellectual disabilities to pursue economic and personal freedom, but also leads them to achieve it in a systematic way. This can only be accomplished in a culture that goes beyond mere toleration to one that warmly welcomes and appreciates persons with intellectual disabilities. This is our challenge, this is our "charge."

A new road map is required, one that aligns a public rhetoric to desired outcomes. It needs to be based on the principles of the self-determination movement that has been evolving since 1993. These principles are: **freedom** to live a meaningful life in the community; **authority** over dollars needed for support; **support** to organize resources in ways that are life-enhancing and meaningful; and **responsibility** for the wise use of public dollars.³⁶

There are a myriad of issues that impact on the quality of life experienced by citizens with intellectual disabilities and their families. The Committee has special concerns relating to faulty attitudes currently held by the general public, particularly employers, affecting people with intellectual disabilities in our society. It is also concerned about the existence of a form of enforced poverty among citizens with intellectual disabilities that may be the result of certain well-intended public policies.

Our American citizens with intellectual disabilities need access to a complete range of health care services and supports from medical, dental and other health professional providers. Certain aspects of education in our nation need significant improvements to effectively prepare students with intellectual disabilities in academic, behavioral and vocational areas. Employment is a major problem area, with an unacceptable rate of 90 percent unemployment. Closely associated with this is the need for asset development and the opportunity for opening one's own savings account without the fear of loss of benefits for citizens with intellectual disabilities. At the same time, we need to retain a social safety net since many people with intellectual disabilities may not ever be able to have sufficient assets to become totally independent. Special consideration needs to be given to control of resources by persons with intellectual disabilities and their families to ensure meaningful long-term development. Existing compartmentalized programs do not offer these persons control over resources.

For successful community living for Americans with intellectual disabilities and their families, there is a need for assistive technology in education and employment, and increased availability of appropriate and adequate transportation and housing. Finally, the government needs to improve the way it assesses programs to arrive at better outcomes.

Freedom is an American virtue. Its basic premise is that *all people* are created equal *and* "are endowed by their Creator with certain unalienable rights, among which are life, liberty and the pursuit of happiness."³⁷ As a nation, we must ensure that these words do not reflect empty promises. Rather, these words must hold true to inclusion and opportunities to pursue the American Dream by *all persons*, including those with intellectual disabilities.

Mr. President, the PCPID has noted the fact that this report to you arrives at the outset of the 21st Century. This realization has permeated our thinking about matters of substance, style and presentation. Our document is neither a scholarly dissertation nor a detailed strategic plan. It is a road map to personal and economic freedom for a group of individuals and their families, for whom we share a common concern: "It is a Charge We Have to Keep."

Public Awareness

1. The PCPID invites and encourages you, Mr. President, to participate as the Committee's spokesperson in a national campaign specifically targeted to school-age children and employers to change negative public attitudes toward people with intellectual disabilities. The campaign should include a variety of media, including public service announcements, print and television features, and a web directory to assist employers to identify individuals with intellectual disabilities who are seeking employment. The Committee is eager to collaborate and is prepared to partner with corporations that already have had positive experiences hiring individuals with intellectual disabilities.
2. The Committee is partnering with the Special Olympics to change negative public attitudes toward people with intellectual disabilities.

Performance Management

1. Establish a strategic partnership with the Office of Management and Budget, an appropriate non-governmental agency, and with the PCPID and other relevant federal agencies. The partnership would create a set of practical performance measures for agencies that administer federal programs that have an impact on people with intellectual disabilities to hold them accountable for the advancement of outcomes that improve personal and economic freedom. These measures and performance indicators should be comprehensive, consistent, and complementary.
2. Apply an enriched PART to 20 percent of the government's generic and disability specific programs each year, beginning in FY 2004, with follow-up recommendations to address poor performance, and an annual report to Congress on the status of the improved program performance and outcomes.
3. Urge Congress to conduct at least annual oversight hearings in the House and Senate to assess cross-agency performance with the advancement of outcomes that improve personal and economic freedom for people with intellectual disabilities. Such joint hearings should extend beyond traditional lines of authority to embrace a holistic view of individual and family support that analyzes relationships among tax, finance, economic, education, health care, and workforce policies.

Education and Transition from School to Work and Adult Life

1. Develop meaningful assessments and accountability by establishing an Intra-Agency Task Force, which would be facilitated by the U.S. Department of Education and include national experts, to provide ongoing guidance to states on universally relevant standards and appropriate assessments for students with intellectual disabilities under the No Child Left Behind Act.
2. Support and promote the idea that the Jobs for the 21st Century initiative should improve reading instruction, acquisition of reading skills, improvement in post-secondary outcomes and improvement in post-secondary employment opportunities for all individuals with intellectual disabilities.
3. Develop relevant standards that apply to skills and competencies required in the work setting through a collaboration with the U.S. Departments of Education and Labor to apply the findings of the 1991 Secretary's Commission on Achieving the Necessary Skills (SCANS).³⁸
4. Support quality teacher training and professional development to help all teachers learn to elevate the achievement of all students, including students with intellectual disabilities.

5. Increase post-secondary opportunities by providing opportunities for students with intellectual disabilities.
6. Develop a seamless pre K-16 system of instruction and support to remove barriers that limit the ability of federal resources—including Social Security, Medicaid, special education, vocational education and other general education and human services resources—to be pooled with state and local funds to support students with intellectual disabilities while in high school, as they enter the workforce or post-secondary education.
7. Foster community-based initiatives, as part of the Jobs for the 21st Century initiative, that lead to improved employment and post-secondary outcomes for students with intellectual disabilities.

Employment and Asset Development

1. Authorize a streamlined process and accelerated timetable for states to secure approval of a dual waiver through the Social Security Administration and the Centers for Medicare and Medicaid Services that provide incentives to work, and accumulate assets for individuals with intellectual disabilities without losing their eligibility for benefits.
2. Propose the establishment of Qualified Disability Savings Accounts (QDS As) to encourage individuals with intellectual disabilities and their families to participate in long-term planning and savings, which will advance personal and economic freedom. Moreover, a QDSA would not exclude a person from receiving government benefits.
3. Explore the structure of current Individual Development Accounts (IDAs) to determine whether they would require modification for qualified persons with intellectual disabilities to use as a savings account. Expand the opportunities to save for purposes based upon an individual's own needs without losing benefits.
4. Establish a strategic partnership with the U.S. Departments of Labor, Education, Transportation and Commerce, the Centers for Medicare and Medicaid Services, the Social Security Administration, the Equal Employment Opportunity Commission and the Small Business Administration to promote employment of people with intellectual disabilities. In concert with the PCPID, these eight federal agencies have the expertise and experience to leverage current employer relationships to stimulate new investment and support of individuals with intellectual disabilities in the workplace. An appropriate agency, like the Department of Commerce or Labor, should assume the leadership role in convening five forums concerned with employment of people with intellectual disabilities.

Forum 1: Convene a forum of small business leaders to promote a better understanding of the strengths of people with intellectual disabilities as employees and to discuss and resolve current issues concerned with employment of people with intellectual disabilities in small business establishments.

Forum 2: Convene a forum of large business leaders to promote a better understanding of the strengths of people with intellectual disabilities as employees and to discuss and resolve current issues concerned with employment of people with intellectual disabilities in large business establishments.

Forum 3: Convene a forum of human resources leaders to discuss and resolve current issues concerned with employment of people with intellectual disabilities, including appropriate announcements for jobs, appropriate application forms for employment, appropriate techniques for recruitment and selection of employees, appropriate pre-employment education and on-the-job training opportunities for improvement of performance by employees with intellectual disabilities, and other areas as may be identified.

Forum 4: Convene a forum on network capacity building, at the local level, with voluntary organizations for developing knowledge and skills for individuals and families on how to enter the job market and develop desirable personal contacts and supports.

Forum 5: Convene a forum of leaders from the transportation industry, advocacy organizations for people with intellectual disabilities, rehabilitation service organizations and federal agencies to develop initiatives targeted at improved access to transportation systems by people with intellectual disabilities. Access to transportation is pivotal to the employment, medical and health care, and education of people with intellectual disabilities.

Family Services and Supports

1. Authorize a streamlined process and accelerated timetable for states to secure approval of a dual waiver through the Social Security Administration and the Centers for Medicare and Medicaid Services that provide incentives to work and accumulate assets for people with intellectual disabilities without losing their eligibility for benefits. This recommendation is repeated because it was developed by both the Subcommittee on Family Services and Supports and the Subcommittee on Employment and Asset Development.
2. Establish an Interagency Task Force on Developmental Health that is facilitated by the Centers for Disease Control and Prevention with the PCPID, and includes representatives from the Centers for Medicare and Medicaid Services, the Administration on Developmental Disabilities, the Bureau of Health Professions, the Agency for Health Research and Quality, and private sector organizations.
3. Commission longitudinal studies to: 1) design new financing options and assess their impact on service access and delivery to persons with intellectual disabilities, and 2) examine provider attitudes, behaviors relative to inclusion of persons with intellectual disabilities in community-based and private practice settings.

4. Relieve restrictions for meeting Medicaid eligibility for persons with disabilities when family members work by raising the income threshold for Medicaid eligibility.
5. Convene a "White House Conference on Respite Care" to identify model service approaches that benefit families with members with intellectual disabilities.
6. Conduct housing demonstration projects that include support services for adults transitioning from in-home dependent care to independent living environments. Encourage the Department of Housing and Urban Development and the Centers for Medicare and Medicaid Services to collaborate with states to test affordable and accessible community housing models that promote independence and offer supportive services when needed.
7. Support and promote respect for the civil rights, liberties and dignities of people with intellectual disabilities, which need to be respected in the environment of anti-terrorism tactics and strategies as developed and practiced by the Department of Homeland Security and related agencies.

Assistive Technology and Information

1. Support the establishment of a network of "Research Centers of Excellence in Technology and Intellectual Disabilities" to engage in research and development on new technologies to improve the quality of life, wellness, and independent living of people with intellectual disabilities.
2. Encourage White House leadership to convene a meeting of relevant agencies, including the Departments of Labor, Education, Transportation, Commerce and the Equal Employment Opportunity Commission, to promote access to technology which advances the employment opportunities of people with intellectual disabilities.
3. Convene a forum, coordinated by the PCPID, to identify new and improved strategies to stimulate manufacturers' investment in design and development of products that advance independence and the productivity of people with intellectual disabilities. The PCPID urges that a major emphasis be placed on the creation of a common architecture in the development of assistive technology. In addition, emphasis should be placed on the creation of synergy between government funding and assistive technology access and use in the home, workplace, and community.
4. Encourage the Departments of Education and Labor to fund a series of demonstration projects that emphasize public and private sector coordination and investment.

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