



## REPORT TO THE PRESIDENT

*HOLDING TRUTHS TO BE SELF-EVIDENT:*

*AFFIRMING THE VALUE  
OF PEOPLE  
WITH INTELLECTUAL DISABILITIES*

2007



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OF PEOPLE  
WITH INTELLECTUAL DISABILITIES***

**2007**

*Dedicated, affectionately, to the Memory of George N. Bouthilet, Ph.D.  
former Research Director  
The President's Committee for People with Intellectual Disabilities*

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

Dear Mr. President:

I forward for your consideration the 2007 Annual Report of the President's Committee for People with Intellectual Disabilities (PCPID). The report provides advice on matters that pertain to the field of intellectual disabilities and people with intellectual disabilities.

Committee members organized their advice to you within the conceptual framework of the "inherent value" of people with intellectual disabilities, the challenges they face, and the opportunities that affirm their value. The Committee seeks to heighten the awareness of leading governmental officials and lay Americans regarding policies and practices that impact the lives of citizens with intellectual disabilities.

Committee members applaud and embrace the goals in your New Freedom Initiative (NFI). The NFI notes that many Americans with disabilities "remain outside the economic and social mainstream of American life." This reality results in increased challenges and additional quality of life issues related to housing and health. Providing core ideas to affirm the value of people with intellectual disabilities is what has motivated the Committee members, many of whom are parents, siblings, or relatives of a person with an intellectual disability, and have personal knowledge of this reality.

This Report offers recommendations that will create increased options and opportunities and affirm the value of Americans with intellectual disabilities.

It should be noted that this document does not necessarily reflect the views of the United States Department of Health and Human Services. Although some of the information and data contained in this report were contributed by authorities in the field of disability, research, education, housing, emerging technology, public policy 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 United States Department of Health and Human Services, or other Federal Government agencies.

Although the term "mental retardation" (MR) appears in several sections of this Report, particularly in reference to biomedical research where the term is still widely used, PCPID acknowledges and advocates for use of the term "intellectual disability".

Sincerely,

Michael O. Leavitt

The President  
The White House  
Washington, DC 20500

Dear Mr. President:

On behalf of the President's Committee for People with Intellectual Disabilities (PCPID), I wish to express appreciation for the honor to serve your Administration and the American people. We support and are committed to the fulfillment of the mission of the Committee to provide advice and assistance to you and to the Secretary of Health and Human Services on a broad range of topics that relate to people with intellectual disabilities, and to the field of intellectual disabilities. For many of us, it is a personal relationship with an individual with an intellectual disability that provides the positive motivation in our lives to work to improve the quality of life that is experienced by people with intellectual disabilities and their families.

When considering and discussing the status of the national effort to remove barriers that prevent full inclusion of people with intellectual disabilities in community living as most Americans know it, the Committee was struck with the regrettable reality that people with intellectual disabilities are, too often, excluded because they are undervalued or believed to be less worthy of full citizenship. Committee members decided to explore specific ways to heighten public awareness of the inherent value of people with intellectual disabilities; particularly with regard to education, housing, health, technology, the criminal justice system, and application of research findings. We are pleased to share the results of this exploration with you and the White House Staff.

Mr. President, members and staff of the President's Committee for People with Intellectual Disabilities appreciate the opportunity to submit for your consideration the Report, *HOLDING TRUTHS TO BE SELF-EVIDENT: Affirming the Value of People with Intellectual Disabilities*. The intended outcome of this Report is to promote further understanding on the part of leading government officials, as well as lay Americans, of the inherent value of people with intellectual disabilities, and appropriate public policy that reflects this understanding. We are hopeful that the Report will facilitate early realization of the Committee's mission to improve the quality of life that is experienced by people with intellectual disabilities and their family members.

Sincerely,

Dallas "Rob" Sweezy  
Chair

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## Committee Profile

Although there is no national census of the incidence and prevalence of intellectual disabilities, authorities in the field estimate that the number may be as high as 2 percent of the population, six million individuals. One in 10 families in the United States is directly affected by a person with intellectual disabilities. In order to ensure the right of a “decent, dignified place in society” for people with mental retardation (intellectual disabilities), President Lyndon B. Johnson established, in 1966, the Committee on Mental Retardation (PCMR), now the President’s Committee for People with Intellectual Disabilities (PCPID), to focus on this critical subject of national concern. Since that time, the President’s Committee has served in an advisory capacity to the President and the Secretary of Health and Human Services on a broad range of matters relating to persons with intellectual disabilities and the field of intellectual disabilities.

Since its inception, the President’s Committee has led the charge to improve the lives of people with intellectual disabilities, most recently embracing the vision and supporting the plan that is at the heart of President George W. Bush’s New Freedom Initiative (NFI) to tear down barriers that prevent people with intellectual disabilities from enjoying a quality of life that promotes independence, self-determination, and full participation as productive members of society. The NFI includes, but is not limited to: increasing access through assistive and universally designed technology; expanding educational opportunities for youth with disabilities; and promoting full and lifelong access to all aspects of community life.

The Committee consists of 21 citizen members appointed by the President and 13 ex officio heads of Federal Government departments and agencies designated by the President. The 13 ex officio members include: the Attorney General, Secretary of the Interior, Secretary of Commerce, Secretary of Labor, Secretary of Health and Human Services, Secretary of Housing and Urban Development, Secretary of Transportation, Secretary of Education, Secretary of Homeland Security, President and Chief Executive Officer of the Corporation for National and Community Service, Commissioner of the Social Security Administration, Chair of the Equal Employment Opportunity Commission, and Chair of the National Council on Disability. The President’s Committee for People with Intellectual Disabilities is led by an Executive Director, also appointed by the President, and supported by a team of Federal employees.



## Executive Summary and Recommendations

In fulfillment of its Executive Order to prepare an annual report to the President, the President's Committee for People with Intellectual Disabilities submits its 2007 Report, *HOLDING TRUTHS TO BE SELF-EVIDENT: Affirming the Value of People with Intellectual Disabilities*. The Report offers recommendations in the following three areas that impact the daily lives of people with intellectual disabilities:

- a) The New Freedom Initiative
- b) Effective and Timely Application of Basic Research
- c) Heightening Public Awareness of the Value of People with Intellectual Disabilities

The Report addresses the issues and concerns related to these three areas that have been identified by people with intellectual disabilities, their family members, self-advocates and advocates, researchers, service providers, constituency group representatives, and allied Federal and state agencies and organizations.

In the area of the **New Freedom Initiative**, established to tear down barriers to full community participation for Americans with disabilities, the Report explores ways to further progress for people with intellectual disabilities through the following recommendations:

1. Increase access to emerging technology, and base public policy regarding information and technology accessibility on market driven incentives.
2. Expand educational opportunities and improve instruction and assessment for students with intellectual disabilities, and support implementation of the Least Restrictive Environment (LRE) provisions found in the Individuals with Disabilities Education Act (IDEA) by strengthening the dissemination and application of education research and best practices on accessing the general education curriculum for students with intellectual disabilities.
3. Promote full access to community life and integrate Americans with intellectual disabilities into the community by improving the availability of community-based housing and necessary staff to support people with intellectual disabilities.
4. Encourage State Medicaid Directors, not currently doing so, to initiate and sustain efforts to ensure that all Medicaid-eligible children in every state have access to Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) services to help reduce the incidence and prevalence of intellectual disabilities, mitigate its effects, and increase access to appropriate health care.

In the area of **Research Application**, the Committee recognizes an opportunity to speed the flow of basic scientific findings – both positive and negative – into the clinical environment through the following recommendations:

1. Foster continued intensified efforts to streamline the translation of basic scientific findings into clinical applications.
2. Encourage the vigorous pursuit and development of new technologies and approaches for early screening, detection, diagnosis, amelioration and treatment.
3. Establish an Ad Hoc Federal Interagency Council on Research Translation for the Benefit of People with Intellectual Disabilities, with membership from appropriate Federal agencies, advised by pertinent non-governmental organizations.

In the area of **Public Awareness**, the Report encourages the Federal Government to dispel long-held myths regarding people with intellectual disabilities, and demonstrate their value and competence to Federal, state and local officials, and the American public through the following recommendations:

- Lead by example by including in the State of the Union Address, Weekly Radio broadcast, and other public appearances, statements of support, stories of inspiration and statistical data on the contributions of people with intellectual disabilities.
- Mandate that every program throughout the Federal Government, that was established to address a single or range of specified needs of individuals diagnosed with a physical or mental impairment that substantially limits one or more of the major life activities of such individuals, set aside a percentage of its total budget to increase public awareness of the program's existence and purpose.
- Establish a National Disability History Week to instill in our communities an understanding of the value of people with disabilities.
- Increase the commitment to support DisabilityInfo.gov so that it may better fulfill its mission to provide increased access to vital information and resources.
- Encourage and provide the necessary training to those working in the criminal justice system to facilitate recognition of the competency and value of people with intellectual disabilities to the criminal justice system, both as victims and witnesses.

## SECTION I: The New Freedom Initiative

When the groundbreaking policy, *The New Freedom Initiative*, was introduced on February 2, 2001 Americans embraced it as an important step toward ensuring that all Americans with disabilities, whether young or old, can participate more fully in the life of their communities and of our country.

Good work has been accomplished, but there is work yet to be done. We must continue until all people with intellectual disabilities are fully recognized and appreciated for their inherent, God given value, and are included as full participants in their communities. To demonstrate its commitment to this goal, the Committee chose to examine concerns, issues, challenges, and barriers related to full and lifelong inclusion of people with intellectual disabilities in the following focus areas of the New Freedom Initiative:

1. broadening access to emerging technologies.
2. expanding educational opportunities for youth through increased access to general education inclusion.
3. promoting full access to community life through more community housing and home ownership.
4. targeting examination of Medicaid's youth health program – Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) services – which focuses on prevention and intervention of intellectual disabilities in children and youth.

# Emerging Technologies

## Background and Rationale

### **Strengthening the Commitment to Accessible Cognitive Support Technologies**

The New Freedom Initiative 2007 Progress Report clearly conveys the commitment to promote partnerships for people with all disabilities to gain greater access to the workplace, school and community life through technology. However, the promise of technology for individuals with intellectual disabilities has not been fulfilled. There is a reticence in the rehabilitation technology field to address the challenge of developing accessible technology for individuals with intellectual disabilities. Even among disability professionals, there are often misconceptions about the “inability” of individuals with intellectual disabilities to use technology. However, evidence-based research has consistently shown that individuals with intellectual disabilities can effectively utilize properly designed cognitive support technology.<sup>1</sup> Cognitive technologies include products that “aid a person’s cognitive functioning (comprehension, perception, memory, problem solving and reasoning.)”<sup>2</sup>

### **The Promise of Cognitive Support Technologies**

Technology can be an equalizer and promotes independence, productivity and improved quality of life by increasing access to education, employment, healthcare, and community living that people without disabilities often take for granted. More than fifty years ago, the field of assistive technology began to create a myriad of life-changing technologies for people with physical and sensory disabilities. Regrettably, the development of technologies designed to address the specific needs of individuals with intellectual and cognitive disabilities has lagged far behind that of other disabilities. Now, formative research and development, and the recent availability of new cognitive support technologies, offer individuals with intellectual and developmental disabilities some of the same kind of opportunities to benefit from technology.<sup>1</sup> The following three real-life examples demonstrate ways that cognitive support technologies empower people with intellectual disabilities.

*JAY uses a picture and audio e-mail program designed for non-readers to stay in touch with friends and family. The program uses a picture address book and enables users to speak and automatically send e-mail messages verbally. Incoming email shows the picture of the sender and, when selected, reads the incoming message out loud.<sup>3</sup>*

*MICHAEL’S enthusiasm for life knows no bounds. He hasn’t let his physical and intellectual challenges prevent him from overcoming one of the few barriers that continued to frustrate him – the inability to gain functional reading skills. Michael uses an accessible electronic book reader prototype. His own words best summarize*

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<sup>1</sup> M.L. Wehmeyer et al, “Technology Use and People With Mental Retardation,” in L.M. Glidden (ed.), *International Review of Research in Mental Retardation*, Vol.29, San Diego, CA, Academy Press, 2004, pp. 293-337.

<sup>2</sup> <http://www.memoryzine.com/cognitivetechnology.html#AUTHORS>. Accessed on October 18, 2007.

<sup>3</sup> User of Web Trek Connect, accessible e-mail program ([www.ablelinktech.com](http://www.ablelinktech.com)).

*his success: “Now I can read a book for the first time in my life! I know what I’m getting for Christmas – BOOKS!”<sup>4</sup>*

*JON is a 46-year-old man whose intellectual disability presents challenges to his highly social, community-based lifestyle. Access to his network of friends has been confounded by the complexities of travel on the public transit system. A GPS-supported Pocket PC system for independent travel on the buses provides John with a personal cognitive aid that supports his newfound independence. He now has confidence in knowing where to get on the bus, how long to stay on, and ultimately, when to ring the bell and successfully get off at his desired destination.<sup>5</sup>*

The benefits of computer use by people with intellectual disabilities have been highlighted recently in the *International Review of Research in Mental Retardation*<sup>6</sup> and have been demonstrated in many educational, vocational and independent living settings.<sup>7</sup> For example, computers have been used to teach vocational tasks,<sup>8, 9</sup> for anti-victimization training,<sup>10</sup> language acquisition,<sup>11</sup> as a motivational tool,<sup>12</sup> for menu planning,<sup>13</sup> for independent Internet access,<sup>14</sup> for indicating career preferences<sup>15</sup> and for decision-making support.<sup>16</sup> Computer use by individuals with intellectual disabilities leads to:

1. enhanced self-esteem—People with intellectual disabilities are not only unafraid of computers, they seem very anxious for an opportunity to use them.
2. increased independence—Studies have shown that self-directed use of computers by people with intellectual disabilities to perform various vocational and independent living tasks can significantly reduce the amount of assistance required from others.
3. self-direction—Computer-generated audio prompting provides an increased sense of control and empowerment to users with intellectual disabilities.

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<sup>4</sup> User of Rocket Reader, accessible e-book program ([www.ablelinktech.com](http://www.ablelinktech.com)).

<sup>5</sup> User of WayFinder, accessible transportation aid ([www.ablelinktech.com](http://www.ablelinktech.com)).

<sup>6</sup> Wehmeyer, pp. 293-337.

<sup>7</sup> Ibid.

<sup>8</sup> D.K. Davies and S.E. Stock, “PictureCoach and PocketCoach: An Integrated Multi-Media Training System for Teaching and Maintaining Vocational Skills for Adults With Developmental Disabilities,” Phase I SBIR Final Report, U.S. Department of Education, March 1997, available through Ablelink Technologies, [www.ablelinktech.com](http://www.ablelinktech.com).

D.K. Davies and S.E. Stock (1997) *PictureCoach and PocketCoach: An Integrated Multimedia Training System for Skill Development for Individuals with Mental Retardation*, Phase II SBIR Final Report, U.S. Department of Education, March 1997, available through Ablelink Technologies, [www.ablelinktech.com](http://www.ablelinktech.com).

<sup>9</sup> D.K. Davies and S.E. Stock, “Visual Assistant: A Portable Multimedia Training System for Community-Based Skill Development for Individuals with Mental Retardation,” Phase I Final Report, U.S. Department of Education, March 1999, available through Ablelink Technologies, [www.ablelinktech.com](http://www.ablelinktech.com).

<sup>10</sup> C.S. Holzberg, “Technology in Special Education,” *Technology and Learning*, April, 1994, pp. 18-22.

<sup>11</sup> C.S. Holzberg, “Technology in Special Education,” *Technology and Learning*, February, 1995, pp. 18-23.

<sup>12</sup> G. Keyes, “The Time on Computer Program,” *Teaching Exceptional Children*, Fall, 1994, pp. 20-23.

<sup>13</sup> S.E. Stock, S.K. Davies and A.O. Ocken, “NutraNet: An Internet Based Self-Directed Multimedia Nutritional Planning and Grocery Shopping System for Individuals with Mental Retardation,” Phase I SBIR Final Report, U.S. Department of Education, March, 2001, available through Ablelink Technologies, [www.ablelinktech.com](http://www.ablelinktech.com).

<sup>14</sup> D.K. Davies et al, “Enhancing Independent Internet Access for Individuals With Mental Retardation Through the Use of a Specialized Web Browser: A Pilot Study,” *Education and Training in Mental Retardation and Developmental Disabilities*, 36(1), 2001, pp. 107-113.

<sup>15</sup> S.E. Stock et al, “Self-Directed Career Preference Selection for Individuals With Intellectual Disabilities: Using Computer Technology to Enhance Self-Determination,” *Journal of Vocational Rehabilitation*, Vol. 19, 2003, pp. 95-103.

<sup>16</sup> D.K. Davies et al, “A palmtop computer-based intelligent aid for individuals with mental retardation to increase independence and self-determination in decision-making,” *Research and Practice for Persons with Severe Disabilities*, Vol.28 No.3, 2003, pp. 182-193.

4. efficient use of time—Studies have repeatedly shown that the amount of time required from teachers, staff or family members to assist in the completion of daily living, vocational and educational tasks can be reduced significantly with appropriate computer use.

### **Challenges and Opportunities**

Fewer than 25 percent of people with disabilities who could be helped by assistive technology (AT) use it.<sup>17</sup> Of that 25 percent, those with intellectual disabilities often use out-dated or even obsolete technologies that no longer work efficiently.<sup>18</sup> Their experiences are generally less than optimal, in part because the AT was designed for other populations and does not address their special needs. Consequently, there is a high abandonment rate. The functional characteristics and user interface of any technology system must be designed with consideration of the physical, perceptual, and intellectual characteristics of the end-user population. Mainstream developers, and even many AT developers, have historically not considered the needs of users with cognitive disabilities in the design of their systems. Mainstream consumer preferences encourage developers to add more functionality into smaller devices resulting in more complexity and less accessibility to people with intellectual disabilities. The incorporation of universal design principles is critically important to assure that accessibility is not compromised. In contrast, emerging cognitive support technologies are proving to have the potential to better address many of the needs of individuals with intellectual disabilities. New cognitive technologies, applications of existing technologies, adapted devices and improved web accessibility can level the playing field and provide meaningful opportunities for individual achievement.

The rapid advancement of mainstream technology presents an unprecedented opportunity to give millions of Americans the chance to live more productive lives, yet the development of the necessary assistive (and cognitive) technology policies, standards, and incentives are not keeping pace. In many cases, existing policies or standards do not apply, and there is a trend toward weakening current accessibility standards which would create further barriers to accessibility.

An example of this trend is the proliferation of electronic forms of media for education and recreation. In response to increased security concerns, the present momentum is toward a closed system for digital rights management (DRM). Optical media technology has provided vast improvements in the delivery of data as seen in the move from analog music (vinyl records) to optical digital recordings (CDs/DVDs). However, piracy concerns have led to the introduction of security features that can prevent people using assistive technology from accessing the content. While such a closed system results in accessibility problems for all individuals, people with intellectual disabilities are most significantly impacted because their ability to participate in society is often dependent on the availability and accessibility of technological supports.

The ever increasing use of the World Wide Web creates special challenges. There is increasing reliance on the web for communications, entertainment, access to information, and commercial transactions. Consider, for example, the self-advocate who attempts to access health insurance

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<sup>17</sup> M.J. Scherer, "Technology for improving cognitive function, Report on a workshop sponsored by the U.S. Interagency Committee on Disability Research, *Disability and Rehabilitation: Assistive Technology*, September, 2006, Vol. 1, No. 4, pp 257-261.

<sup>18</sup> Ibid.

information only available online or a consumer who wants to shop online because talking with a sales associate in a store may be too difficult. Accessibility in online access, webpage design and navigation, and content are all areas of research and development that hold great promise. Without attention to the creation of new policies and standards, inaccessibility to the web will continue to contribute to the serious and growing digital divide. Fortunately, there is increased attention to the needs of people with intellectual disabilities in the standards and policy community, including the U.S. Access Board and the World Wide Web Consortium. Increased technical input to these groups and increased participation by self-advocates is needed to support their efforts.

An economic case for cognitive support technologies and increased accessibility can be easily made. One example is the relationship between intellectual disabilities and the natural aging process that often leads to declining attention spans, memory loss, and diminished problem solving skills. As more baby boomers age, many may find that they share some of the characteristics of individuals with intellectual disabilities. As a cohort, they create a large “market opportunity.” Consequently, research and development of new kinds of assistive and cognitive support technologies combined with regulatory standards to increase accessibility can be economically viable. A parallel example might be curb cuts that have assisted not only persons with physical disabilities in wheelchairs, but also cyclers and mothers with baby carriages.

Noteworthy, is the fact that the National Institute on Disability and Rehabilitation Research (NIDRR) is funding several impressive projects that focus on cognitive technologies. First is the Rehabilitation Engineering and Research Center for the Advancement of Cognitive Technologies (RERC-ACT). The goal of this RERC is to research, develop, evaluate, implement, and disseminate innovative technologies and approaches that will have a positive impact on the way in which individuals with significant cognitive disabilities function within their communities and workplace. The Center incorporates: (1) a consumer-driven model for identifying the most significant barriers to independent living and workforce; (2) an approach that is balanced and uses both well-established and newly emerging technologies in its development projects; (3) a focus both on functional limitations and specific disabilities; and (4) mutually beneficial partnerships with private industry and public agencies. Research activities include: Needs, knowledge, barriers, and uses of AT by persons with cognitive disabilities; influences on AT use, non-use, and partial, and inappropriate use by persons with traumatic brain injury; AT enhancement of written expression for children and adults; needs assessment for creating affordable, context-aware technologies; and technology to promote decision-making skills and self-determination for students with cognitive disabilities. Development activities include: Design, implementation, and deployment of context aware technologies for persons with cognitive disabilities residing in community living environments; development of HealthQuest, an Internet-based product that enables individuals with intellectual disabilities to become active participants in their own health care; XML repository of common tasks; batteryless micropower sensors for context aware technologies; perceptive animated interfaces for workforce training; and environmentally appropriate behavioral cues for individuals with TBI.<sup>19</sup>

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<sup>19</sup> Cathy Bodine, “Rehabilitation Engineering Research Center for the Advancement of Cognitive Technologies (RERC-ACT),” University of Colorado, <http://rerc-act.org.html>, accessed November 8, 2007.



Second is the Web Accessibility Initiative (WAI) Phase II that develops technical solutions and educational resources to increase accessibility of the Web for people with disabilities, and works with organizations around the world to promote awareness and implementation of Web accessibility solutions. For millions of individuals with visual, hearing, physical, cognitive and neurological disabilities, accessibility of the Web means access to the information society: to educational opportunity, employment, commerce, government services, and more. WAI Phase II activities include (1) ensuring accessibility support in a broad range of Web technologies through ongoing review of all World Wide Web Consortium (W3C) specifications for new Web technologies, and through liaison with other organizations developing Web technologies; (2) developing advanced guidelines and techniques for accessible Web content, for browsers and media players, and for authoring tools, and providing in-house technical assistance to software developers on implementation of accessibility guidelines in their products; (3) developing expanded techniques and resources for more effective evaluation of Web site accessibility; (4) developing a broad array of educational and outreach resources and activities promoting awareness and implementation of Web accessibility, including online and hard-copy resources, introductory materials for general audiences and technical materials for more advanced audiences, best-practice training resources and events, reference lists of tools, policies, and events, and liaison to other standards organizations interested in Web accessibility; and (5) analysis of potential accessibility issues in research and development related to advanced Web technologies.<sup>20</sup>

Third is the Assistive Technology and Cognitive Disabilities project that assesses the use of several types of information technologies by children and adults with cognitive disabilities, specifically individuals with TBI and mental retardation. Outcomes include: (1) a catalog of existing portable devices for memory and organization, (2) a list of features that enhance or inhibit use of these general purpose and special-use technologies, (3) results of needs surveys regarding use of these technologies, (4) white papers describing project findings, (5) tip cards to assist families in purchasing devices, (6) stronger partnerships between the consumer and research and development communities, and (7) recommendations for memory and organization device modifications and features for individuals with brain injury and mental retardation. The Brain Injury Association, Inc. leads and administers this collaborative partnership, which includes the Traumatic Brain Injury Model Systems Projects at Moss Rehabilitation Research Institute and Spaulding Rehabilitation Hospital, the Institute on Disabilities/Center for Excellence on Developmental Disabilities at Temple University, and the University of Akron.<sup>21</sup>

The information received from the National Institute on Research and Rehabilitation Research and reported in the preceding paragraphs, as well as information from other researchers in the field of cognitive technologies, indicates that assistive technology is on the verge of a transformative revolution that can benefit all of mankind; but only if we invest in its adoption, standardization and accessibility. The emergence of inexpensive technologies such as the Internet, wireless broadband, personal digital assistants and global positioning make the vision of assistive technology as a “prosthesis for life” a real possibility within the decade.

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<sup>20</sup> Tim Berners-Lee, Massachusetts Institute of Technology W3C Accessibility Initiative, WA1/11/01/2004 <http://www.w3.org>, accessed November 8, 2007.

<sup>21</sup> Roberta DePompei, Ph.D., Assistive Technology and Cognitive Disabilities, University of Akron School of Speech-Language Pathology and Audiology, Project Number H133A030810, <http://www.uaakron.edu/colleges/faa/depts/sslpa/faculty/Depompei.php>, accessed November 8, 2007.



## **Conclusion**

Current technology trends reflect a move away from accessible interfaces, just at the time when technological advances can provide breakthrough advances for people with intellectual disabilities. Emerging cognitive technologies have the capacity to improve the quality of life for people with intellectual disabilities and other cognitive challenges. Universal design principles need to be applied to enable greater customization of user interfaces to address the specific needs of individuals with intellectual disabilities. Policy decisions and incentives for accessibility are critical components of the commitment to promote the ability of people with intellectual disabilities to live full, productive lives.

## **Recommendations**

1. Convene stakeholders including consumers, caregivers, transdisciplinary practitioners, service providers, foundations and trade associations in the field of cognitive technology for a national collaborative summit. The stakeholders would develop a more specific roadmap for research, development and capacity building. A sample of the objectives of the forum includes:
  - Devising an open system for digital rights management so accessibility standards may be developed while meeting the security concerns that drive the trend toward closed systems.
  - Recommending accessible Application Program Interfaces (APIs) and community source projects in software development to ensure accessibility while providing for private sector proprietary product protection.
  - Developing and promoting cross-platform accessible APIs to reduce substantially the cost of accessible software.
  - Recommending Federal incentives such as tax breaks and new grant programs for stakeholder partnerships.
2. Base all public policy regarding information technology accessibility on market driven incentives. Harnessing the power of the marketplace and highlighting the financial benefits of accessibility in all products meets the needs of all customers, including people with intellectual disabilities. In addition to encouraging the marketplace to create products that are accessible to everyone, the Committee recommends that the President encourage the Interagency Committee on Disability Research (ICDR) to continue discussing policies and directions that support efficiency of the marketplace for the benefit of people with intellectual disabilities. This may include the following action steps:
  - wide dissemination of information about successful projects
  - wide dissemination of requests for proposals

- establishment of policies that set appropriate industry standards and promote valid research

In doing so, market forces, in tandem with well defined accessibility policies and practices, will produce business models that provide a clear profit advantage to those who comply, and a clear profit disadvantage to those who do not.

3. Support the continuation of NIDRR's support of research for the advancement of cognitive technologies.

## **Moving Toward Equity within Education Least Restrictive Environment**

*Education is the key to independent living and a high quality of life... The Administration will expand access to quality education for Americans with disabilities.*

President George W. Bush  
New Freedom Initiative  
February 1, 2001

### **Background and Rationale**

All people, including students with intellectual disabilities, desire to be respected and valued by those with whom they come into contact. Promoting awareness that all students have value to our schools and to our society will help people become more accepting of individual strengths and differences. Acceptance of diversity usually develops within the family, then within the school environment, and is subsequently carried into the workplace and community.

Since the enactment of the Education of All Handicapped Children Act in 1975,<sup>22</sup> – renamed the Individuals with Disabilities Education Act (IDEA) in 1990,<sup>23</sup> and amended in 1997 and 2004 – “more students with disabilities are attending schools in their own neighborhoods – schools which may not have been open to them previously. Fewer students with disabilities are in separate buildings or separate classrooms on school campuses, and are instead learning in classes with their peers.”<sup>24</sup> This practice of welcoming, valuing and empowering students with varying disabilities in the general education classroom with their non-disabled peers is a direct outgrowth of the section of IDEA that addresses “Least Restrictive Environment.” Inclusive education, wherein students of varying abilities attend their neighborhood school and take part in social and academic learning, is considered by many to be the heart and spirit of Least Restrictive Environment (LRE).

Over the past 30 years, there has been a positive change in the perception and practice of including students with intellectual disabilities within the general education classroom. This change, however, has been slow. For students with intellectual disabilities, the opportunity to attend the neighborhood school and access the general education curriculum in the regular classroom is still far behind that of students with other disabilities. The opportunities for these students to attend their neighborhood school and engage in general education curriculum within the regular classroom will need to be increased if we hope to attain the President’s goals for people with disabilities to “participate more fully in the life of their communities and of our country” and not be “dismissed or forgotten.”

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<sup>22</sup> Public Law 94-142

<sup>23</sup> Public Law 101-476

<sup>24</sup> “IDEA’s Impact: Thirty Years of Progress in Educating Children with Disabilities Through IDEA,” US Department of Education, Office of Special Education and Rehabilitative Services, <http://www.ed.gov/policy/speced/leg/idea/history/30html>, accessed on September 17, 2007.

## **Challenges and Opportunities**

The 2005 *Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act* notes that as of fall 2003, only 11.66 percent of students with intellectual disabilities were being served in the most inclusive setting within the public school system. Thus, of all students ages six through 21, with *any* identified degree of intellectual disability<sup>25</sup> served under the IDEA, only a small portion spend as much as 80 percent of their day in the regular classroom.<sup>26</sup>

The Committee believes that segregated programs for students with intellectual disabilities are isolating, and lead to more restrictive services and more limited lives within the community. Segregated settings do not result in the promotion of students to regular education status over time. In other words, more restrictive education settings do not prepare students for less restrictive ones; nor do more restrictive education settings tend to promote the most successful transition of children and youth, K-12, to post-secondary school, work and community life.

In the same 2005 Annual Report to Congress cited above, statistics show a wide disparity of students with intellectual disabilities in the most inclusive setting from state to state. The fluctuation of these students in the most inclusive setting ranges from a low of 3.65 percent in Texas, to a high of 59.11 percent in Vermont.<sup>27</sup> This presents great challenges for families as they move from one state to another, and even from one district to another. The assumption that similar provisions of LRE will be available in the new state or district is often dispelled during the first meeting with new school personnel. Increased equitability of enactment and interpretation regarding LRE under IDEA would ease the transfer of students with intellectual disabilities from district to district and state to state. Under IDEA, alternative placements listed in the definition of special education and related services include instruction in regular classes, special classes, special schools, home instruction, and instruction in hospitals and institutions.

The continuum of least restrictive educational choices for parents and their children needs to be broadened to allow more students to move more fully into inclusive settings. States should ensure that, to the maximum extent appropriate, children with intellectual disabilities are educated with children without disabilities. A variety of educational placement choices may be considered when focusing on Least Restrictive Environment during development of an Individualized Education Program (IEP) for students receiving special education services. The LRE options that are reviewed and agreed upon by the IEP team should be those which are of the most benefit to the individual child, so that he or she and his or her peers, might learn best in an environment that is characterized by high expectations, rigorous curriculum and opportunities for all students. Special classes, separate schooling, or other removal of children with disabilities from the regular educational environment should occur only if the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily. Thus, the objective is not just to have children with

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<sup>25</sup> The 2005 "Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act" categorizes children with intellectual disabilities as children with mental retardation.

<sup>26</sup> "27<sup>th</sup> Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act," U.S. Department of Education, Office of Special Education and Rehabilitation, Office of Special Education Programs, Vol. 2, 2005, pg. 200.

<http://www.ed.gov/about/reports/annual/osep/2005/parts-b-c/index.html>, accessed on September 17, 2007 via PDF format.

<sup>27</sup> Ibid.

intellectual disabilities stop in to general education classrooms through mainstreaming activities, but to be an integral part of the class community, to engage in grade-level content to the best of their ability, and to strive toward grade-level standards in accordance with their IEP goals.

In order for students with intellectual disabilities to realize the benefits of LRE within the regular classroom setting, inclusive education must be provided with excellence. Quality inclusive education requires that administration, staff, and most important, teachers, be well trained and receive sustained support. In an inclusive classroom setting, the learning environment is significantly affected by the teacher's perception and understanding of children with intellectual disabilities, and the degree to which the teacher's perception and understanding influences his or her interactions with students. Realizing that the inclusive classroom setting creates by definition a broad diversity of student needs, teachers do require this sustained support to create effective classroom environments for each student. For example, additional training in special education and, specifically, on students with intellectual disabilities, may result in increased awareness and appreciation of the value of these students and increased provisions for quality inclusive education for all students. Quality inclusive classrooms offer children the opportunity to fully experience student life, which helps them formulate a positive self-image and improves their academic performance. When students with diverse abilities are included, they come to recognize they are of value to their community. Inclusion can benefit all people involved – teachers, students, and parents.

Another important aspect of providing inclusive education in the 21<sup>st</sup> century is movement toward a Universal Design for Learning (UDL). The term universal design refers to the creation of places or things that are accessible to as many people as possible, such as speakerphones and close-captioned television. When applied to education, the term universal design generally refers to elimination of barriers to educational places or materials—for example, providing accessible textbooks. More comprehensively, Universal Design for Learning is a research-based framework for designing curriculum and instruction – educational goals, methods, materials, and assessment – which enables all individuals to gain knowledge, skills, and enthusiasm for learning. This is accomplished by simultaneously providing rich supports for learning and reducing barriers to the general education curriculum, while maintaining high achievement standards for all students. UDL encourages the use of diverse instructional strategies, such as differentiated instruction, enabling teachers to provide better access to rigorous curriculum. Architects design buildings from the start to be accessible to everybody, avoiding the need to fix accessibility problems after the fact. Similarly, educators must view UDL as a process of flexible and supportive design for learning that, from the start, allows teachers to meet the needs of diverse learners. Thus, UDL helps educators customize their teaching for individual learning style differences in students. The embedded UDL features facilitate the efforts of educators to better teach and support students with intellectual disabilities. Universal Design for Learning uses the power and flexibility to make education more inclusive and effective for all learners.

Many general education teachers may not be prepared to work effectively with students who have intellectual disabilities. General education teachers may lack current and on-going training, and may not always be equipped to handle the day-to-day reality of meeting the diverse learning needs of each child. Teachers will benefit from opportunities to learn about best practices and researched-based teaching strategies in differentiated instruction. Access to models of inclusive

classrooms that promote participation and progress in the general education curriculum help prepare teachers and increase their understanding of strategies that work to help students with intellectual disabilities reach their full potential.

The October 2002 report of the President's Commission on Excellence in Special Education recommended improvements in the development and dissemination of research findings that will increase teacher and parent access to effective educational practices and instructional methods.<sup>28</sup> There has been progress in information dissemination since then, and it is hoped these advances will continue to be improved upon, to further the provisions for students with intellectual disabilities to learn general education curriculum in the least restrictive environment. General education teachers must have access to current research and best practices in order to prepare to work effectively with students with intellectual disabilities. Anecdotal evidence suggests that most colleges and universities require students pursuing a general education degree to take one three- to four-hour survey course focused on students with various disabilities. Across the country, for teachers entering the education field through alternative route programs, it is likely they will have had no formal training that prepares them to effectively teach students with intellectual disabilities in an inclusive setting.

## **Conclusion**

Academic and social benefits may be observed for a majority of students when Least Restrictive Environment provisions are enacted equitably and when inclusive education is implemented effectively.<sup>29</sup> Attitudinal barriers of prejudice break down, friendships develop, and students without disabilities are motivated to achieve increased academic and social gains. Successful inclusion is then carried from the home and school environment into the workplace and community.

## **Recommendations**

Improve instruction and assessments for students with intellectual disabilities and support and promote full, equitable, implementation of the Least Restrictive Environment provisions of IDEA by:

1. Encouraging increased use of Universal Design for Learning in the educational setting. Use communication and outreach resources of the United States Department of Education (ED), as well as cutting edge communication technology such as DisabilityInfo.gov, to provide information to state and local departments of education regarding the universal design of curriculum, materials, instruction and assessments.
2. Strengthening information bridges from the Federal Government to state and local departments of education, schools, teachers and parents by providing current, research-based strategies and best practices related to students with intellectual disabilities.

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<sup>28</sup> "A New Era, Revitalizing Special Education for Children and Their Families," President's Commission on Excellence in Special Education, 2002, pp. 59-67, <http://www.ed.gov/inits/commissionsboards/whspecialeducation/reports/index.html>, accessed on September 17, 2007.

<sup>29</sup> Margaret McLaughlin et al, "Effective Education in the Least Restrictive Setting," K. Charlie Lakin and Ann Turnbull (eds.), *National Goals and Research for People with Intellectual and Developmental Disabilities*, Washington, DC, American Association on Intellectual and Developmental Disabilities (formerly American Association on Mental Retardation), 2005, pg. 51.

3. Publishing and fully disseminating findings of the U.S. Department of Education, Office of Special Education Programs, of current directed studies and projects related to students with intellectual disabilities, such as those that focus on determining what kinds of early interventions promote the best results for students with disabilities, and increase understanding of access to the general education curriculum for students with significant cognitive disabilities, as noted in both the 2004 “New Freedom Initiative: A Progress Report”<sup>30</sup> and the 2002 President’s Commission on Excellence in Special Education Final Report to the President.<sup>31</sup>
4. Supporting increased technical assistance to facilitate teacher efforts to implement evidence-based and promising practices demonstrated in inclusive school models. Increasing availability of existing research findings that demonstrate evidence-based and promising practices will improve the ability of general education teachers to teach students with intellectual disabilities in regular education classrooms.

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<sup>30</sup> “New Freedom Initiative: A Progress Report,” 2004, pp. 4, 17, <http://www.whitehouse.gov/infocus/newfreedom/toc-2004.html>, accessed on September 17, 2007.

<sup>31</sup> “A New Era: Revitalizing Special Education for Children and Their Families,” pp. 59-67.

# Housing for People with Intellectual Disabilities

## Background and Rationale

Historically, people with intellectual disabilities have been denied the opportunity to live as independently as possible in their own communities. Many have been limited to remaining in large institutions where they live apart from the mainstream community. Others, whose families have supported their son or daughter at home into adulthood, ultimately find themselves less a part of their community as their parents advance in age—often due to a lack of community integration supports and services. This lack of independent housing choices and unnecessary isolation is an unfortunate reflection of the lack of value society at large sees in the lives of people with intellectual disabilities. Because society often does not view people with intellectual disabilities as people with intrinsic value, for many, their isolation continues and they remain invisible.

Being part of the community and living as independently as possible are among the more important values and goals shared by people with disabilities, their families, friends and advocates. Although housing options for people with intellectual disabilities have increased over the past 20 years, there is still need for more affordable community-based residential options that will permit them to live and integrate into their communities. As the availability of large state-operated facilities has declined, so has the state's role as a residential service provider. Many large state facilities have been shut down or have decreased in size, and many more people with intellectual disabilities are living in smaller residential settings. For example, in 1977, 83.7 percent of persons with intellectual disabilities and related developmental disabilities (ID/DD) receiving residential services lived in residences of 16 or more people; by 2005, 70.8 percent lived in residential settings with 6 or fewer people.<sup>32</sup> Also, in 1977, 62.9 percent of all residential service recipients lived in state residential settings. By 2005, that percentage declined to 12.8 percent.<sup>33</sup>

As the number of state residential settings declined, the number of residential service settings run by non-state agencies increased. Of all residential service settings in 2005, 2,469 were operated by state agencies, with the remaining 149,853 residential settings operated by non-state agencies.<sup>34</sup> While these numbers indicate that more people with intellectual disabilities who desire to do so are living in community settings than in years past, the data also suggest that many others may not have access to the housing they and their families seek. Although the overall percentage of those living in large state facilities has declined, 42 states still operate at least one such large facility.<sup>35</sup> Since the average annual amount needed to care for a person in a large state facility is slightly over \$148,000, as compared to the lower cost of other residential services, this is a major financial drain on resources that could be applied elsewhere.<sup>36</sup>

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<sup>32</sup> R.W. Prouty et al, "Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2005," University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration, 2006, p. iii.

<sup>33</sup> Ibid p. vi.

<sup>34</sup> Ibid p. iv.

<sup>35</sup> Ibid p. iii.

<sup>36</sup> Ibid p. iv.



Another pressing problem is the large number of people still waiting for appropriate housing. While numbers specific to intellectual disabilities are not available, a 2005 estimate of people with developmental disabilities indicates that approximately 74,000 are on a list for residential services.<sup>37</sup> Given that approximately 750,000 people with developmental disabilities live with an aging parent,<sup>38</sup> the number of people waiting for residential services can reasonably be expected to grow.

A major gap exists between the Supplemental Security Income (SSI) on which many people with disabilities rely for their basic needs, and the cost of living in a supported environment that public programs, alone, cannot meet.<sup>39</sup> In many areas of the country, state and local officials have concluded that creating and maintaining community residences or group homes for people with intellectual disabilities who want them is a crushing financial burden. Public officials are often challenged in their efforts to create more group homes or other supported housing for people with intellectual disabilities. The expansion, and perhaps even the maintenance, of supported apartments or group homes will have to be borne by private efforts or by private-public partnerships. Often, non-profit or even for-profit organizations run group homes for persons with intellectual disabilities. The cost is often divided among the residents, their families, the housing providers and, in some instances the state or local government.

The *Olmstead* discussion in the President's New Freedom Initiative recognized the need to create more community housing placements to move residents of institutions into more appropriate community facilities. In July 2006, through the Money Follows the Person Rebalancing Initiative, the Centers for Medicare and Medicaid Services (CMS) in the U.S. Department of Health and Human Services dedicated \$1.75 billion over the next five years to move more than 100,000 people with disabilities out of nursing homes and other institutional settings and into community-based settings. While this represents significant progress, more can be done by building upon that momentum.

Many states and local communities have made commendable efforts to provide affordable housing. Generally, however, those efforts have not encompassed housing for persons with intellectual disabilities, even though they are among those with the lowest incomes and most in need of affordable housing. For example, the four million Americans with disabilities who rely on monthly SSI for all their basic needs would have to pay 109.6 percent of their entire monthly income to rent a modest one-bedroom unit.<sup>40</sup> Many affordable housing efforts provide housing for low-income families, while ignoring the needs of people with intellectual disabilities who clearly meet the definition of those in need of affordable housing.

Many people with intellectual disabilities need varying levels of staff support. This support can range from 24-hour a day staff for individuals with profound impairment to periodic support for individuals with moderate or mild levels of disability. But support staff is essential to the provision of a safe and inclusive environment.

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<sup>37</sup> Ibid p. vi.

<sup>38</sup> "Fact Sheet – Housing for People with Disabilities: The Crisis Escalates," The Arc, 2007  
<http://www.thearc.org/NetCommunity/Page.aspx?&pid=1343&srcid=217>, accessed on October 18, 2007.

<sup>39</sup> Ann O'Hara and Emily Cooper, "Priced Out in 2004: The Housing Crisis for People with Disabilities," Technical Assistance Collaborative, Inc., Consortium for Citizens with Disabilities Housing Task Force, 2006. p. I (Forward by Senator Jack Reed).

<sup>40</sup> Ibid p. 40

Supported housing is facing a national shortage of direct support professionals. In 2000, the median hourly wage of personal and home care aides was \$7.50 and the median hourly wage of home health aides was \$8.23.<sup>41</sup> Low wages in this field contribute to staff shortages and high turnover. Without qualified professionals, community-based programs may be unable to survive, or forced to employ people who may not have all the necessary skills. In many areas of the country, particularly those with a high cost of living, employers may not have the necessary funds in their budget to hire and retain well-trained support staff.

In homes supported by Medicaid waiver money, often the funds are not sufficient to attract and retain well-qualified support staff to provide rehabilitation services. Medicaid rules prohibit residents from supplementing the cost of these services with personal Medicaid dollars as the payments made directly to the providers are considered payment in full. In those group homes where expenses are paid by the residents who receive SSI and/or another source of income, rather than by Medicaid, the cost of attracting and retaining good staff must be passed on to residents. These residents are among the lowest paid in our society, and often in only part-time employment, and unable to afford necessary increases. And while some may have parents, siblings, or friends able and willing to subsidize those costs, many simply do not. Costs for staff and for the maintenance of group homes continue to rise. For housing providers, the yearly increase in the cost of living requires raising staff salaries. The rising costs of gasoline, heating oil or gas, and electricity must be matched by increases in income to permit the providers of group homes to keep pace.

Given the factors listed above, many adults with intellectual disabilities who desire independent living have no reasonable opportunity to live away from their parents' homes or institutional settings, and thereby are deprived of a greater degree of independence. In addition to providing community-based housing, group homes also afford significant social interaction for adults with intellectual disabilities. Many adults who remain at home may be deprived of significant social interactions. In turn, parents who, into their old age, choose to care for their adult children with intellectual disabilities may themselves be deprived of social opportunities that many adults take for granted.

### **Challenges and Opportunities**

Many providers of services and supports to people with intellectual disabilities advocate moving to more consumer-based housing options. Even when housing options are available, people with intellectual disabilities often are not afforded control over, or a voice in, basic decisions regarding where they live, with whom they live, and how they spend their time. Much of the housing available to people with intellectual disabilities remains primarily service system controlled, as opposed to consumer controlled. In addition, in many instances individuals who choose to live in Federal and state-supported housing typically face rigid entrance and exit criteria. When personal support is available, it is often one size fits all and linked to the housing, making it difficult for people receiving assistance to exercise choice about their housing options, or sometimes to remain in their preferred housing when their individual needs change. The

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<sup>41</sup> "Fact Sheet – Direct Support Workers," The Arc, 2007, <http://209.190.209.4/NetCommunity/Document.Doc?&id=137>, accessed on October 18, 2007.

individual's preferred housing choices, or those of his or her family, are often defeated by the structure of the housing opportunities provided.

Because most people with intellectual disabilities have limited financial resources with which to own or lease their own homes, it is frequently necessary to identify and combine complex financial mechanisms to bridge the gap between their income and the real cost of housing. These mechanisms may include a combination of low interest rate financing, government or private grants, or rental or homeownership subsidies. Some states have made an effort to help individuals with intellectual disabilities secure housing of their own, either rented individually or owned. Tenant-based rental assistance, Section 8 of the U.S. Housing Act, administered by the U.S. Department of Housing and Urban Development, state trust fund resources, and State tax credits have been used.

Enhancing consumer control provides the individual with more options to choose whom to live with, where to live, and to control the choice of necessary support staff. Self-advocacy organizations are critical to advocating for community-based living, self-determination, and effective services and supports at the local, state, and national level. However, this effort will nonetheless need the kind of governmental and private assistance described above in the area of independent housing opportunities. The creativity of the public and private sector is also needed to improve the lives of people with intellectual disabilities and their families. Governors' councils on developmental disabilities, present in every state, may prove to be a particularly powerful way of reaching individuals with intellectual disabilities and the organizations that represent them, along with a whole host of social service providers, local government agencies, and local and state decision-makers from the non-profit, public, and private sectors.

## **Conclusion**

The value society gives individuals is most often reflected in the efforts society makes to include those individuals among us. With stable and supported housing, people with intellectual disabilities are able to achieve other important goals, including advanced education, job training, and employment. When we encourage the participation of people with intellectual disabilities in all aspects of community living, welcome them into their chosen neighborhoods and schools, and invite them to join and actively participate in government and civic organizations, it reflects an acknowledgment that their contribution and friendship is of value to us. Living in the community among family, friends and neighbors, is the preferred housing option for all people, including people with intellectual disabilities.

## **Recommendations**

1. Improve access to resources to increase the stock of supported community-based housing

The Section 811 Supportive Housing Program for Persons with Disabilities, operated by the Department of Housing and Urban Development (HUD), provides affordable and accessible housing for persons with severe disabilities. Most Section 811 participants live in supportive housing units developed and managed by non-profits that agree to provide housing for people with disabilities for a minimum of 40 years. This program

can provide more units of supported housing appropriate for people with intellectual disabilities at reasonable cost.

In order for this program to be more effective, the regulatory burdens placed on non-profit grantees must be streamlined. Allowed overhead and profit margins are below those common in rental units built in the private sector, and other construction and settlement service providers must wait until final closing to be paid (sometimes three years after completion of the work). These factors tend to tie up money in the 811 pipeline, and encourage the Office of Management and Budget to consider the program ineffective at expending its resources in a timely manner. Program reform should address these issues. Such reform would allow Section 811 grantees to provide more effective support to people with intellectual disabilities.

The Section 8 program, which provides individuals with vouchers to bridge the gap between income and rent, can also be a critical player in the drive to provide private, community-based housing for people with intellectual disabilities. Individuals may use vouchers to secure adequate housing for themselves, or may combine vouchers with others (roommates) to increase their purchasing power.

The Federal Government should examine its programs that provide mortgage assistance to people with disabilities to make sure that people with intellectual disabilities are able to take full advantage of these programs.

The Federal Government should also, perhaps as a part of the New Freedom Initiative, open discussions with state and local governments about including people with intellectual disabilities when they create programs that increase the amount of affordable housing, or otherwise reduce the cost of housing for people with low incomes. This may be used as an opportunity to publicize the Federal rental or mortgage assistance programs as a way to help address the dire need for supported housing for people with intellectual disabilities. While state and local public housing authorities are probably aware of these HUD programs, they may not be cognizant of their potential to create supported housing for people with intellectual disabilities.

Finally, the Federal Government should look at creative use of tax benefits or tax credits to reduce the cost the private sector may bear in providing housing for people with intellectual disabilities. Currently, developers experienced in the use of tax credits avoid HUD programs because of what is perceived as their regulatory burden; thus, HUD should work to remove any unnecessary or cumbersome regulation and work with the private sector to efficiently navigate the process and overcome any false perceptions.

## 2. Improve resources for staff support

For many residents of supported housing, Medicaid waiver slots and payments are critical. Medicaid payments provide the annual income, in some instances supported by part-time work, that residents need to afford supported housing. It is essential not only that HHS and state governments provide reasonable levels of funding through Medicaid,

but also that increased numbers of waiver slots are provided so that people with intellectual disabilities can get necessary supports to permit them to seek housing outside of institutional settings. Restoration of supportive services grants through HUD's 811 program should also be considered.

The service of direct-care workers is supported by several Federal Government initiatives and programs, such as: a) the *New Freedom Initiative* that assists States in developing systems that support community-based care alternatives, training, support and retention of direct service workers with an emphasis on the provision of a health care benefit for direct service workers; and b) *Medicare's Quality Improvement Organization (QIO) Program: Maximizing Potential* intended to focus on offering, through its infrastructure in each state, technical assistance to providers and practitioners aimed at building their capacity for quality improvement. The Federal Government should continue exploring ways to support the employment of direct-care service providers. These positions continue to be underpaid and underappreciated. There may be innovative, yet practical, ways for Federal agencies involved in education and employment activities to demonstrate the value and dignity of these jobs, and to help states, localities, and the private sector support direct-care services as a career. The Federal Government should maintain the lead in this effort, perhaps through grants, student loans or other forms of assistance to states, educational institutions, or directly to individuals pursuing these careers.

### 3. Support and provide incentives for private-public partnerships

In some areas of the country, private-public partnerships have been very successful in providing housing for people with intellectual disabilities. These partnerships have the potential to expand housing opportunities for people with intellectual disabilities.

The Federal Government should explore ways to publicize the need for providing housing for people with intellectual disabilities through public-private partnerships. The Federal Government has demonstrated to the public that it has the capacity to help those in need. The *Thousand Points of Light* concept and subsequent movement were very effective in illustrating that the private sector can help those in need, and that government is not the only answer to society's needs. The Federal Government can build upon the successes of the New Freedom Initiative by encouraging private sector participation and by increasing public awareness of the dire need for supported housing for people with intellectual disabilities.

# **The Impact of Availability and Accessibility of the Medicaid Program and Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) Services on the Lives of People with Intellectual Disabilities**

*Every life is a gift and must be valued. Government should improve the access of every child to the best health care that will assist in prevention and/or mitigation of the adverse effects of intellectual disabilities.*

*Sharman Word Dennis*

## **Background**

Medicaid is a federally funded state-run program, guided by broad Federal guidelines, that provides medical assistance for individuals and families with limited incomes and resources. Medicaid finances health coverage for 27 million, or more than one in four, of America's children. One of the central services of the Medicaid program is the child health component that provides screening of children for a variety of conditions which, if not discovered and treated early in the life of a child, can result in significant developmental and health problems. This service, known as Early and Periodic Screening, Diagnosis, and Treatment (EPSDT), calls for states to provide children and adolescents access to comprehensive, periodic evaluations of health, developmental and nutritional status, as well as vision, hearing, and dental services. Under Federal regulations, states are given some flexibility in determining the periodicity or timing of the health visits and screenings, but the content of screening services is mandated by law.

## **Challenges and Opportunities**

Data from the Centers for Disease Control and Prevention (CDC) found that, in 2000 in metropolitan Atlanta, Georgia, approximately 1 percent of children age 8-years-old have intellectual disabilities. Intellectual disabilities are more common in boys than in girls, and more common in black children than in white children, with the majority of children having mild intellectual disabilities (approximately 60 percent).<sup>42</sup> EPSDT services can provide much needed health care for Medicaid-eligible children with intellectual disabilities, but many of these children and their families are not utilizing these valuable services.

## **EPSDT Services**

For more than 30 years, Federal law has provided comprehensive health coverage for low-income children through Medicaid for children under age 21.<sup>43</sup> Early and Periodic Screening, Diagnostic, and Treatment services and supports components are designed to target health conditions and problems for which growing children are at risk including, but not necessarily limited to iron deficiency, obesity, lead poisoning, and dental disease. Another important objective of EPSDT is early

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<sup>42</sup> T. Karapurkar et al, "Prevalence of Four Developmental Disabilities Among Children Aged 8 Years—Metropolitan Atlanta Developmental Disabilities Surveillance Program, 1996 and 2000," *Morbidity and Mortality Weekly Report*, 2006, 55 (S S01), pp. 1-9, <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5501a1.htm>, accessed on October 31, 2007.

<sup>43</sup> Public Law 90-248, the Social Security Amendments of 1967.

detection and correction of conditions that can hinder a child's learning and development, such as vision and hearing problems. For children with intellectual disabilities, EPSDT is an important resource in identifying the need for essential medical and supportive services, and in making these services available and accessible.<sup>44</sup>

The federally required components that constitute an EPSDT screen include a comprehensive health and developmental history, a comprehensive unclothed physical examination, appropriate immunizations, laboratory tests (including a blood lead-level assessment), and health education.<sup>45</sup>

Some children with intellectual disabilities have speech, hearing and language challenges, vision impairment issues due to congenital cataracts and/or nystagmus, and motoric issues that result from low muscle tonicity. Many of these conditions can be detected through screenings and appropriate treatment can be provided, under EPSDT, to prevent, minimize, or reduce the negative impact of disability. Other required EPSDT services include:

- Vision Services, including screening, diagnosis, treatment, and eyeglasses.
- Dental Services, including screening, pain management, and treatment of infections, restoration, and maintenance.
- Hearing Services, including screening diagnosis, treatment, and hearing aids.<sup>46</sup>
- Other necessary health care, diagnosis services, treatment, and measures described in section 1905(a) of the Act to correct or ameliorate defects, and physical and mental illnesses and conditions discovered by the screening services.<sup>47</sup>

## **Some Target Populations for EPSDT Services to Children and Young Adults**

### ***Newborn Infants and Children at Risk of Developing Intellectual Disabilities***

Many conditions that cause or influence the occurrence of intellectual disabilities are preventable. EPSDT screenings, interventions and therapies can prevent intellectual disabilities, or mitigate their impact. For example, correction of impaired vision or hearing loss in a child will enable the child to learn more easily and thrive in school, which then leads to improvement in the child's social and adaptive skills. Also, screening, diagnosis and treatment for lead poisoning, a known cause of intellectual disability, can prevent the occurrence of this disability.

### ***Children and Youth with Intellectual Disabilities***

Early and Periodic Screening, Diagnostic, and Treatment services are provided to Medicaid-eligible children who already have intellectual disabilities. These children not only need good health care, but also the kinds of screenings, interventions and therapies EPSDT provides.

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<sup>44</sup> Children with Disabilities: Medicaid Can Offer Important Benefits and Services (GAO/T-HEHS-00-152, July 12, 2000).

<sup>45</sup> Medicaid Early & Periodic Screening & Diagnostic Treatment Benefit, BENEFITS, [http://www.cms.hhs.gov/MedicaidEarlyPeriodScrn/02\\_Benefits.asp#TopOfPage](http://www.cms.hhs.gov/MedicaidEarlyPeriodScrn/02_Benefits.asp#TopOfPage), accessed on October 31, 2007. (SSA §1905(r)).

<sup>46</sup> Ibid.

<sup>47</sup> Ibid.

### ***Teenagers who Become Pregnant, and Their Unborn Children***

Teenagers, are already Medicaid eligible, who become pregnant and are eligible for EPSDT services can receive appropriate pre-natal care, and thereby reduce the risk of giving birth to a child with intellectual disabilities.

### **Conclusion**

When available and accessible, the Early and Periodic Screening, Diagnostic, and Treatment services provided through the Medicaid Program can be effective in the prevention and early identification of intellectual disabilities. Comprehensive health and developmental histories, a comprehensive unclothed physical examination, appropriate immunizations, laboratory tests (including a blood lead-level assessment), and health education and other required EPSDT services effectively identify numerous causes of intellectual disabilities including, but not necessarily limited to: genetic conditions, problems experienced during pregnancy, problems during birth, health problems, and exposure to environmental toxins.

EPSDT services are underutilized throughout the United States in communities of need, and by people in need. Effective and consistent early and periodic screening, diagnostic, and treatment services will reduce the incidence and prevalence of intellectual disabilities, and ameliorate concomitant conditions.

### **Recommendations**

1. Encourage the Centers for Medicare and Medicaid Services (CMS) to develop a team to:
  - Continue collaborating with the National Association of State Directors of Medicaid to collect and disseminate information on individual state EPSDT utilization rates for eligible populations; and expand this activity to include collection and dissemination of information on utilization rates by service (screening, diagnosis, treatment). Funding should be made available for this expanded activity.
  - Collect and disseminate existing published research on disease/disability prevention outcomes related to EPSDT services.
  - suggest, support and/or fund research in collaboration with NIH and/or non-public research entities that informs state policy makers and the general public on whether there is a correlation between access to EPSDT-funded services and reduced incidence and prevalence rates in intellectual disabilities.
2. Encourage CMS to provide incentives that support Medicaid-participating states with less than 50 percent participation rates to actively pursue efforts to increase, by 5 percent annually, the participation of Medicaid-eligible children, especially in the area of newborns, infants and toddlers, and teenagers and young adults under age 21 who are pregnant or may become pregnant, to ensure greater access to and utilization of EPSDT related health services.



3. Encourage CMS to develop and sponsor a national recognition award for states that have implemented EPSDT services as an effective tool to reduce the incidence and prevalence of intellectual disabilities. Services and supports implemented by states highlighted with a recognition award should be widely publicized as best practices to local and state Medicaid agencies.

## **SECTION II: Effective and Timely Application of Basic Research**

Basic research is fundamental to improving the lives and health of people with intellectual disabilities. Research advances have the ability to improve health status, functional ability and quality of life for Americans with intellectual disabilities – advances that may take the form of new preventive approaches, adaptations, treatments or cures. There is a balance between scientific discovery in basic research and application of the discovery through translational research. Government is uniquely positioned to promote the translation of new scientific knowledge into tangible benefits for people with intellectual disabilities. It is imperative that government encourage new technologies to broaden applications of existing compounds, and to ensure that valuable scientific discoveries promptly transition from the basic scientist to the clinician. By investing in research to benefit people with intellectual disabilities, the Federal Government acknowledges the inherent value of people with intellectual disabilities in society and provides the means for a healthier future.

### **Background and Rationale**

Research moves along a continuum from the most basic to increasingly applied investigations. Basic research – the fundamental pieces of knowledge discovered by laboratory scientists - becomes applied when it is translated into useful interventions. Frequently, however, there is a long delay in converting or translating research findings into useful applications. For example, it took decades to translate the initial discovery that penicillium mold kills bacteria into the development of the drug called penicillin.

The goal of translational research is to take the discoveries made at the laboratory bench and determine how they might be applied to preventing, managing or ameliorating the effects of disease or disability. A second, and equally important goal, is to encourage adoption of clinical research findings into community practice. The goals of translational research have been hindered on several fronts. Many basic scientists, who carry out studies in the laboratory, do not have the training to test the safety and efficacy of experimental therapies they may have developed. Likewise, many clinical researchers, who carry out their studies in patients, do not have seamless access to findings that have come out of the research lab. Finally, there has not been an infrastructure in place to facilitate an effective continuum of research from bench to bedside to community.

Scientific discoveries must be translated into practical applications in order to bridge the gap from discovery to delivery and it must be done expeditiously. The following examples demonstrate the power of translational research to improve the daily lives of individuals with intellectual disabilities:

### **The link between basic science research and community intervention**

Intellectual disability is really a symptom for which there are numerous underlying causes, some of which are diagnosable genetic syndromes. Over the past decade, there has been increasing recognition of specific behavioral and cognitive features associated with many of these syndromes. Research into syndrome-specific behaviors and learning styles provides a

customized approach to meeting the needs of individuals, rather than the general, one size fits all approaches that have previously been applied to individuals with intellectual disabilities. For example:

- People with Smith-Magenis syndromes, a developmental disorder that affects many parts of the body and is sometimes accompanied by intellectual disabilities, often severely bite or pick at their fingernails and toenails. This behavior appears to be related to problems with nerve functioning in the hands and feet due to the deletion of part of chromosome 17. Such basic research knowledge helps to focus on the physiological causes of self-injurious behavior in Smith-Magenis syndrome, rather than simply trying to alleviate the behavior without understanding the reason for it.<sup>48</sup>
- Educators have found greater success in teaching reading to children with fragile X syndrome when they use a whole word approach versus traditional phonics. Laboratory research laid the foundation for this customized educational approach when scientists identified the deficits in sequential processing associated with fragile X syndrome.<sup>49</sup>

### **The link between basic science research, diagnosis and prognosis**

An early diagnosis helps a family understand their child's therapeutic, educational and social needs. Etiologically, however, people with intellectual disabilities are a heterogeneous group. There are occasions when physicians cannot provide a definitive medical diagnosis, and the current state of knowledge and technology is insufficient for the task. The reasons vary. Some children will have a number of problems that do not fit into one specific condition; rare conditions may have no identified diagnostic indicators; there are substantial variations in the degree to which a child may be affected by a disorder or syndrome impeding a diagnosis; certain identifying features may not appear until later in the child's development, resulting in a late diagnosis and missed opportunity for early intervention.

Many parents have described their feelings of frustration as they are referred from one specialist to another, anxiously seeking a diagnosis. Without this information parents can find it difficult to obtain the services and supports that will maximize their child's development and inclusion. Undeniably, eligibility criteria for some state and Federal programs are based on the presence of specified medical diagnoses. For example:

- Some clinical conditions can be definitively confirmed. The diagnosis of fragile X syndrome is confirmed by molecular genetic testing of the fragile X mental retardation 1 (*FMRI*) gene. Early identification of the syndrome allows for timely intervention and involvement in programs developed specifically for children with fragile X syndrome. On the other hand, clinical conditions for which there are no definitive diagnoses present ambiguities. Autism Spectrum Disorder (ASD), for instance, has no specific diagnostic test. Although studies on ASD have provided evidence for a strong genetic component,

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<sup>48</sup> E. Dykens et al, *Genetics and Mental Retardation Syndrome: A New Look at Behavior and Interventions*, Baltimore, MD, Brookes Publishing Company, 2001.

<sup>49</sup> Ibid.

and a priority for ASD research is finding a biologic marker for the disorder, there is no such medical test currently available to unequivocally diagnose ASD. Observations and reports of behavior are the only methods for screening and diagnosing ASD. But observational methods are subject to problems of reliability and validity and can often present language and cultural barriers that impede accurate assessment. There are many educational and therapeutic programs that have been developed specifically for children with ASD, and without an accurate assessment of the condition, these useful strategies will be overlooked. In the case of ASD, research that eventually leads to a definitive diagnosis will help reduce reliance on less valid assessments, help families receive appropriate services, and help reduce disparities in services across populations and states.

- Traumatic brain injury (TBI) is a leading cause of intellectual disability among infants and young children. Proper diagnosis of TBI at this age is difficult, even for experienced physicians, due to the subtleties of the injury and the developmental stage of the infant or child. However, laboratory scientists discovered that the presence of TBI can be detected by measuring the levels of specific biomarkers in the blood. This line of research is now being pursued by clinicians and preliminary results are promising. The researchers hypothesize that a positive biomarker test suggests the presence of brain injury and the need for more intensive evaluation. Although the research is still in its infancy, if the approach is successful, it will help to reduce the incidence of missed diagnosis of TBI and ultimately lead to timely intervention during a time when the young brain is still developing.<sup>50</sup>

Continuing research is needed to explore environmental and familial risk factors, MRI findings, and biochemical changes associated with intellectual disability. Through this line of research, hopefully, science will provide greater understanding of all clinical conditions behind intellectual disability. Expedient application of research findings will help reduce barriers to diagnosis and improve timely access to appropriate medical, educational and social interventions.

### **Challenges and Opportunities**

While there can be many reasons important research findings are not translated into useful application or why the findings fail to influence practice or policy, the roadblocks tend to fall into four areas – coordination, dissemination, accessibility and technology transfer.

#### **Coordination**

Many factors interact to produce intellectual disabilities, such as socio-environmental (adverse pregnancy environments or nutrition, for instance) and genetic factors (gender or genotypes, for instance). Therefore, the scientific study of intellectual disability involves researchers from multiple perspectives. However, there is not always communication and coordination among the body of researchers or among the agencies that fund the research. Often, there are no incentives to communicate or coordinate with each other. The reality of the scientific process is that most

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<sup>50</sup> Improving the Diagnosis and Prognosis of Inflicted Trauma in Infants: A five year grant awarded by the Centers for Disease Control & Prevention to the Center for Injury Research and Control at Children's Hospital of Pittsburgh, Patrick Kochanek and Thomas Songer, Investigators, [http://www.neurosurgery.pitt.edu/research/projects/clinical\\_research/circl\\_infant\\_trauma.html](http://www.neurosurgery.pitt.edu/research/projects/clinical_research/circl_infant_trauma.html), accessed May 30, 2007.

discoveries and breakthroughs are built on basic knowledge created over multiple years by multitudes of scientists. Better collaboration between researchers will hasten the translational pathway between basic science and interventions to improve the health and quality of life for people with intellectual disabilities.

### **Dissemination**

Most research findings appear only in targeted academic or scientific journals with little distribution beyond the immediate scientific community. For example, a genetic breakthrough might be communicated within the genetics literature and never reach the environmental researcher studying the interaction of genetics and environment. Research findings do not consistently or systematically reach the larger research domain and certainly not the larger public domain. Little emphasis is placed on linking research into non-research networks and contexts.

Furthermore, there is a well-known bias against disseminating negative research findings versus positive results. Negative findings are those that do not confirm their hypotheses or demonstrate statistically significant effects. In essence, these are experimental failures. The bias can be found among scientific editors who do not publish negative findings and the public which shows little interest in failure. Yet failure in science and medicine is exceedingly important. One of the most important advantages of making failure known is that such knowledge will lead to abandoning ineffective approaches or therapies. Conversely, shielding scientific failure from the larger community fosters unnecessary repetition of research, allows wrong beliefs to persist, and slows technological progress. The Federal Government is in a unique position to encourage investigators to present negative findings at conferences, editors to publish them, and interested communities to pay attention because negative studies provide major impetus for further research.

Medical research can and should be disseminated as efficiently, effectively, and equitably as possible. Published discoveries and ideas are the foundation for future progress; the more widely and freely accessible research findings are, the greater their value to researchers, clinicians, policymakers, and the public. Broadened dissemination of research findings will facilitate basic and clinical research, and accelerate the development of innovations that can positively impact the lives of people with intellectual disabilities.

### **Accessibility**

Gaps in the accessibility of research findings impede the application of emerging good practices. The gap exists, in part, because a lag of several years exists before published research influences practice. Furthermore, findings are not often communicated in a way that they effectively inform decisions about policy or practice. There is a general failure to disseminate the results of research to practitioners, and then to ensure that this dissemination leads to desired changes in practice. A gap exists between research knowledge on the one hand and its impact on people with intellectual disabilities on the other. Closing the information gap between researchers and practitioners is a necessary step if evidence-based innovation is to truly improve the lives of people with intellectual disabilities.

## **Technology Transfer**

In the overall research framework, basic science research in the public sector traditionally leads to new and innovative technology applications in the private sector. Private companies are ultimately the organizations that commercialize research technology and bring new discoveries to the marketplace. This process of transferring technology from federally funded research centers into the private sector has resulted in numerous innovations in health care. However, how the transfer occurs is not always well understood. Technological innovations that might have promising applications for people with intellectual disabilities often fail to get transferred to the private sector. There could be several reasons for this failure. Often, knowledge about the technology is not widely disseminated, nor is it disseminated in a timely manner, leading to a lack of awareness regarding the innovation. In other instances, the failure occurs at the incubation stage, because of lack of support. Sometimes, there are simply no effective channels for the technology transfer.

Effective transfer of technology from the public research system to the private sector is one way to do more with less. It can bring the benefits of basic research in the public sector to people with intellectual disabilities more quickly, and help achieve the overall intellectual disability research mission in an era of relatively scarce public resources. A number of methods are helpful in achieving this goal - direct communication between scientists and end users (i.e., individuals, families, and people who work in the field of intellectual disability), networking among scientists from multiple disciplines, supporting cooperative research, and expediting intellectual property instruments such as patenting and licensing. The existence of effective channels and models of technology transfer would greatly accelerate the application of basic research to end products and services beneficial to Americans with intellectual disabilities.

Despite active research in the field of disability, the combination of these four factors results in a vast amount of research that does not filter down to the primary stakeholders – people with intellectual disabilities, their families, service providers, educators, health care professionals and related researchers. Each of these groups offers unique perspectives, knowledge, and experiences that will potentially inform and challenge new discoveries and deliveries. The net effect is that individuals with intellectual disabilities are not benefiting from research as fully as they could. Moreover, the public receives much less return on their investment than is possible.

If policymakers fail to understand the importance of the continuum of basic, applied, and translational research, the funding and policies that keep discoveries moving forward will always be at risk. Government must work to mitigate this risk.

## **Model Programs**

Encouragingly, the Federal Government has in place several programs with the ability to facilitate an intensified focus on translational research.

### **Developmental Disabilities Research Centers (the Centers)**

The Developmental Disabilities Research Centers, supported by the National Institute on Child Health and Human Development (NICHD) within the National Institutes of Health (NIH), represents America's first sustained and integrated effort to prevent and treat disabilities

through biomedical and behavioral research. Today they are the world's largest concentration of scientific expertise in the fields of intellectual and developmental disabilities. The scope of the research conducted at the 20 Centers encompasses every known major dimension of mental retardation. These Centers, and the network they form, substantially foster communication, innovation, and excellence in research. They work collaboratively on numerous research projects, and together with the Society for Developmental Pediatrics, produce the quarterly publication, "Mental Retardation and Developmental Disabilities Research Reviews." Furthermore, the Centers are engaged in a very important mission - training the next generation of scientific investigators and clinicians in this area of great importance to America's children and families.

Over the last three decades there has been an impressive payoff in the Federal investment in the Developmental Disabilities Research Centers. Many disorders that cause intellectual disabilities can now be prevented or treated to improve developmental outcomes. The Centers' scientific achievements have helped improve the quality of life for individuals and families affected by disabilities.

### **Leadership Education and Neural-Developmental Centers (LENDs)**

The Leadership Education and Neural-Developmental Centers, funded through the Maternal and Child Health Bureau (MCHB), ensure that professionals across eleven major disciplines have the necessary training to meet the needs of children with neurodevelopmental and other related disabilities. They address the unique needs of these children and their families, and provide culturally competent interdisciplinary services. The distinguishing characteristic of these 35 programs is that they are associated with a medical school and/or a children's hospital, and they are the foundation for the interdisciplinary training of developmental pediatricians and clinicians that work in the area of developmental and related disabilities in this country.

One particularly encouraging innovation is the use of family members of people with neurodevelopmental disabilities as co-instructors of their interdisciplinary seminars. This provides a direct connection and relationship between trainees and family members, and facilitates a better understanding of the issues that these families face.

### **University Centers for Excellence in Developmental Disabilities (University Centers)**

The University Centers for Excellence in Developmental Disabilities Education, Research and Service, funded primarily by the U.S. Department of Health and Human Services (DHHS), Administration on Developmental Disabilities (ADD), conduct research and training, disseminate best practices and research results, and demonstrate exemplary clinical practices and community services in the areas of intellectual and developmental disabilities. These 67 centers provide technical assistance at community, state, and national levels and typically have extensive relationships with Federal agencies, state agencies, public schools, advocacy groups, and parent groups in their state. They are electronically connected with each other, as well as their individual state organizations, and could be used, in a very quick and efficient way, to translate and disseminate research findings, practices, materials and information to the community, families and individuals with intellectual disabilities who could benefit from them most. Furthermore, ADD has revealed that some University Centers have committed to doing participatory research with families. This would bring families into the research process from

the very beginning and allow them to participate throughout the entire length of the study, from contributing to the design of the research questions, to disseminating the results.

## **Conclusion**

The work of the Developmental Disabilities Research Centers, LENDs, and University Centers has contributed much over the last several decades and they represent a bright future for scientific discovery, translational research and improved systems of services and supports for people with intellectual disabilities. However, much can be done to more effectively use these resources and more expeditiously translate research into practical application to improve the lives of people with intellectual disabilities.

Many factors interact to produce intellectual disabilities, such as socio-environmental (adverse pregnancy environments or nutrition for instance) and genetic factors (gender or genotypes for instance). Therefore, the scientific study of intellectual disabilities involves researchers from multiple perspectives. The Committee believes that better collaboration between researchers will hasten the translational pathway between basic science and interventions to improve health and quality of life for people with intellectual disabilities.

Investing in people with intellectual disabilities by promoting the expeditious application of research will produce new answers and new technologies. It will provide insight into key areas of medical and behavioral investigation. It will improve options for families and help to develop effective policies. Benefits that might be achieved include: a) translation of new diagnostic and prognostic markers into screening and early intervention programs; b) translation of new insights in etiology into the development of community health preventive practices; and c) translation of identified genes into new therapeutic targets.

The Committee urges the President to continue the Federal Government's commitment to honoring the inherent God given value of people with intellectual disabilities through increased investment in the health and well-being of their future.

## **Recommendations**

1. Foster continued intensified efforts to streamline the translation of basic neuroscientific findings into clinical applications for use by people with intellectual disabilities, their families or those who work with them. Clinical or community applications can include prevention, detection, treatment, interventions or adaptations.
2. Encourage the vigorous pursuit and development of new technologies and approaches for early screening, detection, diagnosis, amelioration and treatment of people with intellectual disabilities, particularly as applicable to improvements in drug development and psychopharmacological approaches for the benefit of people with intellectual disabilities.



3. Encourage Congress to improve research and dissemination research that will promote equitable access to services and supports through:
  - improvement of diagnostic categories and culturally competent assessment instruments for the benefit of people with intellectual disabilities; and
  - standardization of eligibility criteria across program and funding streams for the benefit of people with intellectual disabilities.
4. Expedite intellectual disability research translation to promote and foster consistency in appropriateness, effectiveness and efficiency in delivery of services – medical, education, behavioral -- for the benefit of people with intellectual disabilities from any services that will enhance the quality of life.
5. Urge all Federal research agencies supporting biomedical and behavioral science research to coordinate and expedite translation of research findings to appropriate service and education oriented government agencies for the benefit of all people with intellectual disabilities. Such coordination and expeditious translation will enhance the quality of life for each individual with intellectual disabilities as well as ensure that the Federal government understands the value of each person with intellectual disabilities.
6. Urge all Federal service and education agencies and Federal clearinghouses to receive and review, as permissible, research findings and to expedite research translation into readily utilizable health, educational, social and other related applications for the benefit of people with intellectual disabilities.
7. Encourage contributions from non-government sources to expedite the translation of research findings into clinical and other applications. This includes identifying and enlisting private sector research enterprises, private voluntary organizations, and private foundations, and quasi- government agencies, that seek to improve services and supports for people with intellectual disabilities and their families, and who recognize the importance of the inherent value of people with intellectual disabilities.
8. Urge Federal mental health research, service and education agencies to readily translate and promote research applications toward early prevention, early detection, diagnosis, amelioration and treatment of behavioral, emotional, and social disorders that may be associated with citizens with intellectual disabilities, e.g., fetal alcohol spectrum disorders, fragile X syndrome, autism spectrum disorders when functioning at a level equivalent to intellectual disabilities.
9. Urge the Federal Government to take the lead in advancing basic knowledge by strengthening public-to-private technology transfers.

10. Urge the establishment and support of an Ad Hoc Federal Interagency Council on Research Translation for the Benefit of People with Intellectual Disabilities, with membership from appropriate Federal research, service and education agencies and other pertinent government agencies and clearinghouses as may be determined. Consider inviting and including officials and representatives from appropriate private sector research, service and education entities.

## **SECTION III: Heightening Public Awareness of the Value of People with Intellectual Disabilities**

*We hold these truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty and the pursuit of Happiness.*

The Declaration of Independence

### **Background and Rationale**

All people, including people with intellectual disabilities, are endowed by their Creator with the same inherent value. As such, it is incumbent upon the Federal Government to respect this inherent value and protect the rights and dignity of all people – particularly persons most at risk of being victimized, marginalized, or forgotten. Over the last several years in particular, the Federal Government has made great efforts to improve the daily lives of people with intellectual disabilities through full community inclusion. From the Americans with Disabilities Act and the Individuals with Disabilities Education Act to the New Freedom Initiative, barriers continue to come down and provide new avenues of opportunity.

But no amount of legislation that solely addresses government policy will ever be sufficient to create a truly inclusive society as long as the hearts and minds of the citizens of this country continue to harbor misinformed ideas and attitudes about people with intellectual disabilities. These attitudes are perpetuated through stereotypes, poorly informed mass media portrayals and depictions, antiquated policies and, perhaps most significantly, the lack of personal experience with people with intellectual disabilities. Truly, the most significant barriers to inclusion rest in the minds of individuals who do not recognize the inherent value of people with intellectual disabilities.

### **Challenges and Opportunities**

Government must take a more proactive role in demonstrating, not just the inherent value of people with intellectual disabilities, but their competence, economic value and potential for success. It must promote and encourage opportunities for contribution and lead by example through increased utilization of the talents and skills of people with intellectual disabilities. Government must change the fundamental process of how and why it develops disability programs. By recognizing the potential for people with intellectual disabilities to succeed in American society, government programs and services would become an investment in the future from which it can expect to see a return. This immediately changes the emphasis from the need to provide endless supports to a group perceived as lacking value, to an opportunity to invest in the lives of people who have the potential to become a vibrant and vital part of American society, and the American economy.

The Federal Government can make significant progress toward realization of this goal through the following relatively simple actions.

## **Recommendations**

### 1. Lead by Example

The Committee urges the President to lead by example and set the tone for a shift in public perceptions about the inherent value of people with intellectual disabilities by considering including in the State of the Union Address,<sup>51</sup> Weekly Radio Broadcast, and other public appearances, statements of support, stories of inspiration, and statistical data on the contributions of people with intellectual disabilities. Sending the message that the Federal Government is willing to invest in, and has expectations of people with intellectual disabilities will help change the perception of state and local policy makers, educators, business professionals and community leaders, and open doors of opportunity for people with intellectual disabilities that may not have existed before. This language of investment and expectations must be carried throughout government, permeating every department, program, project, curriculum and statement about people with intellectual disabilities. By reshaping government language, program development and implementation will reflect the fact that people with intellectual disabilities have the desire and potential to reach their goals and lead productive, valuable lives.

### 2. Establish a National Disability Awareness Board

Because of the decentralized nature of disability programs throughout the Federal Government – with programs spread across and throughout most Federal agencies – individuals with disabilities, families and caregivers find it difficult to identify and fully utilize the programs and benefits available to them. Valuable resources continue to go underutilized and the needs of many individuals and families in the disability community continue to go unmet because they are unaware of where the programs are located and how best to utilize them. In order to address this concern, the Committee recommends the President mandate that each disability program throughout the Federal Government set aside a percentage of its total budget to increase public awareness of the program's existence and purpose. The Committee strongly believes that in order to realize the full potential of the New Freedom Initiative, the hearts and minds of the American people must be influenced and educated to recognize the inherent value of people with disabilities. The Committee therefore recommends that a percentage of the money set aside to raise awareness about Federal disability programs should be appropriated and pooled to establish a national public awareness campaign about the lives, value and competence of people with disabilities. In order to maximize the investment, the Committee recommends the establishment of a National Disability Awareness Board. The Board will manage and direct the manner in which the funds are used and can include, but need not be limited to curriculum and program development, and collaboration with other public awareness efforts such as the Ad Council (the leading producer of public service advertisements since 1942).

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<sup>51</sup> In the 2007 State of the Union Address, the President briefly mentioned people with disabilities when he said, "When it comes to health care, government has an obligation to the elderly, disabled, and poor children." <http://www.whitehouse.gov/news/releases/2007/01/20070123-2.html>, accessed on July 11, 2007.

Through the allocation of a relatively small portion of Federal disability program dollars, people with intellectual disabilities, their families and caregivers will have a greater awareness of the programs and services available to them, and society at large will gain a better understanding of the value and competence of the people with intellectual disabilities in their communities.

### 3. Establish a National Disability History Week

History is a roadmap for the future. It helps chart the course ahead by reminding us of how we got to where we are, and in many cases, illustrates just how far we have come. By that same rule, ignorance of our history can lead to repeating past mistakes and traveling down roads already discovered to be ineffective and even dangerous. It is vitally important that future generations are equipped with the historical knowledge necessary to make wise and learned decisions about the future direction of disability policy in this country. To facilitate the efforts of future leaders in this endeavor, the Committee recommends the establishment of a National Disability History Week.<sup>52</sup>

Official celebration of any social movement or group in society serves as an invaluable opportunity for increased education and awareness. This has been true for many minority, religious and ethnic groups who have struggled to secure for themselves and their families the promise of a future with no boundaries and no limitations on their potential for success. For example, Black History Month provides an opportunity for leaders, schools, individuals and communities to discuss important issues in a way that would perhaps not be possible otherwise. It is also a conduit for cultural understanding and creates an avenue for community participation, education and increased cultural, religious and ethnic awareness.

As illustrated by the success of Black History Month, a week designated to focus on disability history will provide an invaluable opportunity for increased awareness and education about people with disabilities. It could be used as a vehicle to celebrate the accomplishments of people with disabilities and to highlight past successes in the establishment of disability rights and policies, such as the President's New Freedom Initiative. A week to focus on disability history can illustrate the importance of continuing to strive for full and lifelong inclusion and accessibility for all people with disabilities. It can also serve as a vehicle to heighten public awareness of people with intellectual disabilities as active contributors to their communities, and to diminish public perception of people with disabilities as people only capable of receiving services and supports rather than providing them. People with intellectual disabilities serving side by side with their peers without disabilities provides opportunities for all people to become active contributing members of their community while learning valuable lessons of friendship and acceptance.

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<sup>52</sup> The Committee recommends the third week in October for focusing on disability history. This particular week and month were selected based on a couple of key factors. National Disability Employment Month – another important disability related celebration – already occurs during October; therefore, schools, universities and community organizations are already holding a wide array of disability related events, many of which do not solely focus on employment. Furthermore, efforts within individual states – such as West Virginia which has already established a statewide Disability History Week – have chosen the third week in October to hold their celebrations. Designating the third week of National Disability Employment Month to coincide with state wide efforts will serve to increase the efficacy of the combined efforts.

In addition to its impact on civic and community life, public schools would be able to integrate National Disability History Week into their academic curriculum, providing students with meaningful opportunities to learn about the accomplishments and challenges facing individuals with disabilities. It would also provide students with a forum in which to receive answers to questions that they may otherwise have felt hesitant to ask, particularly in the presence of their classmates with disabilities. It is vitally important that the nation's youth learn that individuals with intellectual disabilities are people with dignity who deserve respect, and, who like everyone else, are not people for whom to feel sorrow, pity or fear. It is equally important that people with intellectual disabilities, particularly youth, hear stories of inspiration that can provide hope, a sense of pride, role models of success, and demonstrate that they, like their peers without disabilities, have a bright future filled with potential for great achievement. The following real life examples demonstrate that people with intellectual disabilities, given opportunity and appropriate support, can succeed in achieving personal goals.

*CHRIS delivers inspirational speeches to university students. He is the goodwill ambassador for the National Down Syndrome Society and serves as the editor-in-chief of its quarterly magazine, Straight Talk. He is also a spokesperson for National Down Syndrome Congress. In 1992, Chris wrote an autobiography, the New York Times Best-Seller, A Special Kind of Hero. The book is dedicated to Chris' biggest fan and look-alike, Scott Muir. Scott contributed a chapter entitled, "Believe in Yourself" in the 1999 book, Down Syndrome: A Promising Future, Together, edited by T.J. Hassold & D. Patterson, and published by Wiley-Liss.<sup>53</sup>*

*LIZ is a leader in the self-advocacy movement. She serves on the Executive Board of the The Association for the Severely Handicapped (TASH) and was formerly active in her local self-advocacy group in New Jersey. She served on the Board of New Jersey TASH, and worked with a state-wide group working to close institutions. On the national level, Liz was Vice President of the national organization, Self-Advocates Becoming Empowered (SABE) from 1993 to 1996. She shares her experiences as a person with an intellectual disability and teaches others how to stand up for their rights. In August, 1998, Liz received the Elizabeth Monroe Boggs Award for Leadership. She was appointed by President Bill Clinton to the President's Committee on Employment of Persons with Disabilities.<sup>54</sup>*

*Ann, of Moultonboro, New Hampshire, is only one of two self-advocates ever appointed to the President's Committee for People with Intellectual Disabilities. She serves on the board of directors of the Direct Support Professionals Association of New Hampshire and the Lakes Region Community Service Council. She has served as a board member of the National Down Syndrome*

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<sup>53</sup> [http://en.wikipedia.org/wiki/Chris\\_Burke\\_\(actor\)](http://en.wikipedia.org/wiki/Chris_Burke_(actor)). Accessed on January 16, 2008.

<sup>54</sup> <http://members.shaw.ca/individualizedfunding/speaker4.htm>. <http://www.nc-ddc.org/publications/People%20First%20Youth-5.pdf>. Accessed on January 16, 2008.

*Congress (NDSC), the New Hampshire Developmental Disabilities Council, and the New Hampshire American Association on Mental Retardation. Ann is founder of two fundraising initiatives: the Ann “UP” Fund for the benefit of NDSC, and the Annie Forts “UP” Syndrome Fund to help children with Down Syndrome all over the country. She also serves as editor of the “Down Syndrome Headline News”. Ann is a popular, nationally recognized motivational speaker and advocate for the needs and rights of people with disabilities, especially those with mental disabilities. She has served as keynote speaker at many national, regional and local conferences, seminars, colleges and schools.<sup>55</sup>*

The need for increased awareness and education is particularly important. A 2003 study found that 80 percent of the population does not personally know a person with an intellectual disability.<sup>56</sup> This lack of meaningful contact fosters the misconception that people with intellectual disabilities cannot significantly contribute to the economy and community. Recent studies indicate that attitudes about people with intellectual disabilities are relatively the same as they were over 50 years ago.<sup>57</sup> However, significant advancements have been made in education and training programs for people with intellectual disabilities that have raised their potential for achievement and success to even greater heights. National Disability History Week can serve as a catalyst to begin a dialogue between people with disabilities, government, schools, advocacy group representatives and the population at large that will serve to bridge the gap between erroneous perception and true potential.

Understanding history lays the foundation for good citizenship, encourages civic responsibility, and inspires behavior that reflects respect for individual differences. Establishing a National Disability History Week provides an opportunity to instill in our communities, places of worship and schools an understanding that people with disabilities, including intellectual disabilities, have inherent and economic value in our society and play a vital role in our nation.

#### 4. Strengthen the Commitment to DisabilityInfo.gov

As government works to change the misperceptions and negative attitudes about people with intellectual disabilities, it is very important that people with intellectual disabilities be given every opportunity to succeed and reach their potential. The ADA, IDEA and New Freedom Initiative have opened many doors and provide invaluable opportunities for education, employment and personal growth, but the fractured and piecemeal nature of many of the programs – that can span several departments, program offices and even Federal and state lines – make it difficult for people with intellectual disabilities and their

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<http://www.unionleader.com/article.aspx?headline=Annie+Forts%3A+She's+able+to+overcome+almost+anything&articleId=24920b37-4f75-4f30-8ddd-cf5df7ff13c>. Accessed January 16, 2008.

<sup>56</sup> As reported by Dr. Gary Siperstein in his presentation to the Committee on February 14, 2007. Dr. Siperstein's presentation was based on statistics from the Multinational Study of Public Attitudes toward Individuals with Intellectual Disabilities. Gary N. Siperstein, et al, "The Multinational Study of Public Attitudes toward Persons with Intellectual Disabilities," Special Olympics International, Washington, D.C., 2003.

<sup>57</sup> Ibid.

families to utilize services and supports that would improve the quality of their daily lives. It is not enough to create new programs and pass important legislation. Federal Government must also ensure that those who would most benefit from the legislation and programs have easy, reliable access to the necessary information.

The 2002 establishment of DisabilityInfo.gov signaled an important step in the effort to address this issue. Federal agencies were directed to launch DisabilityInfo.gov – a web portal that allows subject matter experts from 22 Federal agencies to post to the website news, program and policy updates, and other information about the disability programs and services provided by their respective agencies. The web portal breaks down barriers by connecting people to the resources and information they need to become part of the workforce and community, and live productive, independent lives. With more than seven million visitors to date, and daily visitors that have doubled since 2004, DisabilityInfo.gov has become the leading web portal through which people access information on cross-cutting disability-related subjects.

Because DisabilityInfo.gov represents a significant opportunity for increased access to information that can directly impact the quality of life for people with intellectual disabilities, it must be sustained and strengthened to maximize its efficacy and improve access to vital information. The public, in general, and people with intellectual disabilities and their families, in particular, must be made aware of this important resource and vital part of the New Freedom Initiative. In order to achieve this important goal, the President's Committee recommends the following:

- Encourage Federal agency partner heads to ensure that a representative at the Assistant Secretary or Deputy Assistant Secretary level directly participate in biannual DisabilityInfo.gov Governance Board meetings to guide future improvements to this interagency web portal; and encourage White House/DPC active participation in the Governance Board meetings.
- Direct all Federal agency partners and their relevant sub-agencies to dedicate subject matter experts whose responsibility, within their scope of their mission, is to ensure the timeliness and integrity of the information presented on DisabilityInfo.gov.
- Encourage all Federal agency partners to fund the growth of DisabilityInfo.gov through memoranda of understanding or other appropriate instruments, and/or provide for direct funding of DisabilityInfo.gov to DOL/ODEP in FY 2009.
- Direct all Federal agency partners to DisabilityInfo.gov to dedicate subject matter experts to contribute new content to the web portal regularly, and as needed, regarding time-sensitive grant announcements and news releases related to their disability programs, services and announcements.



- Designate a senior level public affairs representative from each Federal agency partner to help coordinate and expand public awareness of DisabilityInfo.gov, and increase awareness among service providers, advocates and employers of this important resource for people with intellectual disabilities and their families.

## **SECTION IV: Crime Victims with Intellectual Disabilities**

### **Background and Rationale**

People with intellectual disabilities are born with the same inherent value as any other person born in this country and with the same rights recognized and protected by the Constitution of the United States. They share the same right to equal protection under the law guaranteed by the 14<sup>th</sup> amendment, and they share the same authority to exercise that right when a crime is perpetrated against them.

Society has been slow to recognize and afford equal protection to persons with intellectual disabilities. In a small but profound experiment in 1992, Dick Sobsey, of the University of Alberta, gave two groups of law students an identical crime scenario with the exception of one detail. In one scenario the crime victim had an intellectual disability, and in the other, the crime victim had no disability. He then asked each group to determine the sentence the perpetrator should receive. The group sentencing the perpetrator who committed a crime against the person with an intellectual disability gave significantly less jail time than the group sentencing the perpetrator against the person without a disability.<sup>58</sup> Given that recent statistical analysis indicates that the perceived value of individuals with intellectual disabilities has not changed significantly over the past 50 years,<sup>59</sup> it is likely that if that same experiment were conducted today, the results would not be much different.

### **Challenges and Opportunities**

Our culture puts great value on surface beauty, power, intelligence and wealth. These are not characteristics usually associated with individuals with intellectual disabilities. And though these assumptions are false, people with intellectual disabilities are often seen as incompetent, helpless, mentally unstable, slow, lacking awareness, unreliable, and dependent. In the case of violence and victimization, people with intellectual disabilities are often believed to be unable to feel pain, either physical or psychological. It is no surprise then that all available evidence points to the fact that people with intellectual disabilities are abused at rates many times greater than people without disabilities throughout the lifespan.<sup>60</sup>

One of the reasons for the general public's misperceptions about people with intellectual disabilities is their continued lack of personal contact with them. As noted previously in this report, 80 percent of all U.S. citizens do not personally know an individual with intellectual disability.<sup>61</sup> While inclusion efforts have made an impact, particularly among younger generations, increased opportunities for interaction are a vital component of increased understanding. Until people with intellectual disabilities are seen as valued members of our

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<sup>58</sup> Dick Sobsey, *Violence and Abuse in the Lives of People with Disabilities: The End of Silent Acceptance?*, Baltimore, MD, Paul H. Brooks Publishing Company, 1994, p. 323.

<sup>59</sup> Siperstein, 2007.

<sup>60</sup> Joan R. Petersillia, "Crime Victims With Developmental Disabilities: A Review Essay," *Criminal Justice and Behavior*, Vol. 28, No. 6, 2001, pp. 655-694.

<sup>61</sup> Siperstein, 2007.

communities, our efforts to educate, train, legislate, and advocate will not be enough to ameliorate the crime and violence committed against them. With all of the effort at the Federal, state and community level devoted to full, lifelong, community inclusion for people with intellectual disabilities, it is imperative that their rights and needs are recognized and protected.

The societal response of distancing, devaluing and dehumanizing people with intellectual disabilities leads to first responders, social workers, prosecutors, and other professionals that deal with violence to assume that these victims cannot be credible witnesses for themselves and others, or that perpetrators are not worth prosecuting. This kind of societal response can also lead to juries and judicial fact finders determining that the victim with an intellectual disability is unreliable as a witness and has limited value. This lack of awareness can result in denial of equal justice for people with intellectual disabilities.

People with intellectual disabilities, just like the population at large, represent a diverse and multifaceted group. Their abilities vary as do their likes and dislikes. They are no more or less alike than everyone else. A first responder to a crime victim with a disability may encounter someone whose disability is not easily recognizable. This person's behavior may be misinterpreted and labeled as uncooperative. Another victim may have extensive disabilities, leading a first responder to believe that this individual is incapable of accurate reporting, or acting as a witness on his/her own behalf. These are situations where training and increased awareness can make a significant difference in outcome.

Even with education and training, if a first responder does not believe that people with intellectual disabilities have inherent value as individuals, with equal rights to dignity, respect and justice, the outcome may not be optimal. Honoring, promoting and teaching the equal rights of all people in the criminal justice system – including people with intellectual disabilities – must be a vital component of any training and public awareness effort.

## **Recommendations**

1. Encourage increased training for persons working in the criminal justice system on the value of people with intellectual disabilities within the criminal justice system.

Law enforcement agencies and all entities that investigate and prosecute criminal activity should be trained in interfacing with people with intellectual disabilities, including protecting their civil rights. Some resources for training exist through agencies like the Department of Justice's Office for Victims of Crime (DOJ/OVC); however, they reach a very limited number of people. Many Federal agencies are champions of these efforts while others need to investigate how they can be more responsive to this need. Furthermore, such training is often grant-funded and thus sporadic in its availability. Training is typically the single most important activity that can be taken to improve system response and ensure equal access to the justice system for individuals with disabilities, thus a coordinated effort to encourage training should be planned and implemented. Both Title II of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act can, at least in part, serve to meet this need and increase access to the criminal justice system for people with intellectual disabilities.

Section 504 of the Rehabilitation Act<sup>62</sup> states,

“(N)o otherwise qualified individual with a disability in the United States... shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Federal Agency...” Similarly, Title II of the Americans with Disabilities Act<sup>63</sup> states that “no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.”

According to a Department of Justice document entitled *First Response to Victims of Crime Who Have a Disability*,<sup>64</sup> “(B) both Title II of the ADA and Section 504 require – with few exceptions – that first responders provide victims of crime who have a disability with an equal opportunity to benefit from and participate in all programs, services and activities of the law enforcement agency. In addition, first responders must provide for equally effective communication to victims with a disability. Law enforcement, therefore, is required to make reasonable modifications to policies, practices, and procedures where needed to accommodate crime victims who have a disability, unless doing so would fundamentally alter the service, program, or activity the agency provides.” In order to receive Federal funding, states, law enforcement agencies and any other federally funded entity must comply with the requirements of Section 504 outlined above. Training is the most effective and efficient way to meet this requirement. Currently there is no coordinated effort to ensure that agencies and organizations are aware of the full range of their obligations under Section 504, that they have access to the necessary materials to provide adequate training, or that they understand the consequences of non-compliance. In order to ensure full compliance with Section 504, DOJ should take the following actions:

- Develop a grantee information packet, for inclusion in all contracts for Federal funds, to outline the grantee’s obligations under Section 504 and explain the consequences of non-compliance, and provide information on available training through DOJ.
- Improve current, and develop new training materials for use in the law enforcement community that are inclusive of people with intellectual disabilities as witnesses and advocates for themselves and others.

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<sup>62</sup> 29 U.S.C. §794d. See [www.section508.gov](http://www.section508.gov) for section text and additional information, accessed on July 12, 2007.

<sup>63</sup> 42 U.S.C. §12132.

<sup>64</sup> “First Response to Victims of Crime Who Have a Disability,” U.S. Department of Justice, October, 2002. Document number NCJ 195500, <http://www.ojp.usdoj.gov/ovc/publications/infores/firstrep/2002/NCJ195500.pdf>, accessed on July 12, 2007.

- Work to better advertise the availability of these resources to non-grantee departments and agencies to ensure that all law enforcement and first responder agencies and organizations have the most current and accurate resources available to protect the rights of people with intellectual disabilities in the criminal justice system.
2. Increase efforts of the Federal Government to collect data on crime victimization of people with intellectual disabilities.

The disability field has long recognized the need for accurate, reliable data. It is difficult to get the attention of policymakers when little to no data are collected and the data that is collected is not widely circulated and analyzed. The 1998 Crime Victims with Disabilities Awareness Act recognized this need and mandated that the Justice Department begin collecting data on victims of crimes with disabilities. Since that time, the Bureau of Justice Statistics (BJS) has worked to fulfill the mandate of the Crime Victims with Disabilities Awareness Act. However, with limited resources the quality of the data produced thus far has been mixed. BJS has implemented a new questionnaire in 2007 that it expects will produce viable estimates of crimes against people with disabilities, but the data will have some limitations. It will not enable disability specific victimization estimates beyond a few major categories, nor will it collect data on the abuse of people with disabilities living in institutions. Identifying the extent to which people with intellectual disabilities are the victims of crime, particularly in the institutional setting, is vitally important to ensuring the safety of those who may be least able to protect themselves from victimization. Therefore, the Committee recommends that the necessary resources be dedicated to producing accurate, disability specific data on crimes perpetrated against people with intellectual disabilities.

3. Provide Training on Mandated Reporting Laws and Ensure Their Proper Enforcement.

It is imperative that all mandated reporters providing service to individuals with disabilities have an adequate understanding of violence, the dynamics of violence, and their responsibility for reporting it. Government must also ensure that the laws on mandated reporting are strictly enforced. In jurisdictions where mandated reporting laws do not exist, government needs to push for their enactment. One possible remedy is to begin prosecuting providers of services and supports for failing to report cases of violence by people under their employ. This is a violation of law in many jurisdictions that is rarely, if ever, prosecuted. The current prevailing practice for providers is to fire or “let go” of employees they know or suspect have abused their clients, without filing a report documenting the violence. This allows the perpetrator to secure another similar position, putting a new group of people at risk.

4. Encourage advocacy organizations and constituency groups to get involved in efforts to reduce crime against people with intellectual disabilities.

The same advocacy and placement agencies that take the lead in the push for full community inclusion could also become more involved in efforts to reduce violence. These national and state organizations are in a unique position to help ensure that communities minimize the risk of violence against vulnerable citizens while maintaining their opportunities to participate in community activities. Historically, risk reduction efforts have been effective in reducing violence as well as improving disclosure factors (speed of discovery).

5. Encourage the courts to consider the special needs of people with intellectual disabilities when testifying under oath. People with intellectual disabilities can be reliable and accurate witnesses for themselves and others, but can also be put at considerable risk and their testimony compromised in the hands of a prosecutor or defense attorney attempting to take advantage of them.

## Conclusion

At various times in America's history, its leaders have issued the clarion call to its citizens to embrace the true meaning of our national creed that all people are created equal, and that they are endowed with certain inalienable rights. In the 2007 Report to the President – Holding Truths To Be Self-Evident: Affirming the Value of People With Intellectual Disabilities – the President's Committee for People with Intellectual Disabilities affirms its commitment to ensuring that all people, regardless of ability, have access to the rights, privileges and protections enumerated in the Declaration and afforded by the U.S. Constitution. In order to realize this goal, we must, as a nation, recognize that people with intellectual disabilities have value as individuals, as contributors to society and as Americans. We must insist that the inherent rights of people with intellectual disabilities are honored and protected. The Committee urges the President to lead by example and direct all Federal officials to renew with even greater zeal the Federal effort to improve the quality of life, and secure the blessings of liberty for people with intellectual disabilities by implementing the recommendations in this report.

In the area of the **New Freedom Initiative**, established to remove barriers to community inclusion and improve the quality of life that is experienced by people with intellectual disabilities, significant progress can be realized by early implementation of the following actions:

- increasing access to emerging assistive and universally designed technologies.
- improving and expanding educational opportunities in the least restrictive environment.
- promoting and increasing full access to community-based housing opportunities, including home ownership, and opportunities to engage in volunteering or community service.
- ensuring that all eligible children have access to Early and Periodic Screening, Diagnostic, and Treatment services.

In the area of **Research Application**, the daily lives of people with intellectual disabilities will be significantly improved by:

- intensifying efforts to streamline the translation of basic scientific findings into clinical applications.
- vigorously pursuing and developing new technologies and approaches for early screening, detection, diagnosis, amelioration and treatment.
- establishing an Ad Hoc Federal Interagency Council on Research Translation for the Benefit of People with Intellectual Disabilities, with membership from appropriate Federal agencies, advised by pertinent non-governmental organizations.

In the area of **Public Awareness**, long-held myths can be dispelled and the value and competence of people with intellectual disabilities recognized through:

- leading by example by including in the President's State of the Union Address, Weekly Radio broadcasts, and other public appearances, statements of support, stories of inspiration and statistical data on the contributions of people with intellectual disabilities.
- mandating that every disability program through the Federal Government set aside a percentage of its total budget to increase public awareness of the program's existence and purpose.
- Establish a National Disability History Week to instill in America's communities an understanding and appreciation of the value of people with intellectual disabilities.
- increasing the commitment to DisabilityInfo.gov so that it may better fulfill its mission to provide increased access to vital information and resources.
- encouraging and providing the necessary training to people working in the criminal justice system to facilitate recognition of the competency and value of people with intellectual disabilities to the criminal justice system, both as victims and witnesses.



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