



Dignity Through Employment

**The President's Committee
for People with Intellectual Disabilities**

2009 Report to the President

Soon after Dan was born in 1969 with Down syndrome, a doctor recommended withholding a lifesaving medical procedure. When his parents refused, the doctor advised placement in a state institution. But Dan's family had other plans. They mobilized their strong family unit and support from teachers, job coaches, and counselors, as well as Dan's own strong work ethic. In addition to creating an environment where the people in Dan's life learned to see his abilities, this effort led to a job in the Microsoft mail room in Bellevue, Washington. Dan loved his work and was the fastest and most accurate mail sorter in the company. He worked at Microsoft for more than 14 years, until only five days before his death from heart disease at age 36. On the day Dan died, Microsoft flew its flag at half-staff.

Disclaimer

This document, Report to the President—*Dignity Through Employment*, does not necessarily reflect the views of the U.S. 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 employment, disability, research, education, emerging technology, public policy, and related fields, the personal opinions that such contributors may hold or choose to express outside of this Report to the President do not necessarily reflect the views of the President’s Committee for People with Intellectual Disabilities or the U.S. Department of Health and Human Services, or other federal government agencies.

Although the term “mental retardation” (MR) appears in sections of this report, PCPID acknowledges and advocates for use of the term “intellectual disability.”

The individual stories featured in this report are based on personal relationships and publicly available accounts. All of the people featured in the stories have intellectual disabilities.

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Definitions Used in this Report

We define the term “intellectual disability” as “a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before the age of 18. Intellectual disability is the currently preferred term for the disability historically referred to as mental retardation (American Association on Mental Retardation, *Mental Retardation: Definition, classification, and systems of supports*,” Washington, DC, 2002).

We define employment as jobs in integrated, community environments, typical of others in the workforce. Our definition includes competitive wages, employment in companies large and small, and self-employment through people with intellectual disabilities operating strong, vibrant, and profitable businesses of their own. Our definition of employment emphasizes a workplace that integrates people both with and without disabilities in a community-based, non-segregated setting in which workers receive reasonable accommodations and other supports that they need to succeed.

This definition is consistent with the convictions of the President’s Committee for People with Intellectual Disabilities regarding employment outcomes that focus on competitive pay, full integration, an opportunity for career advancement and leadership development, and an arrangement that is mutually satisfying, both to the employee and to the employer. Employment should also involve people with intellectual disabilities in ways to achieve asset accumulation as a vehicle to attain greater economic freedom and achieve the American Dream.

THE PRESIDENT’S COMMITTEE AND ITS ROLE

Estimates of the share of Americans who experience intellectual disabilities vary from less than 1% to 3% (see page 4 hereof). Even at the conservative end of this range (1%), three million Americans experience intellectual disabilities. Nearly 30 million American lives are touched by persons with intellectual disabilities.

To ensure the right of a “decent, dignified place in society” for people with intellectual disabilities, President Lyndon B. Johnson in 1966 established the President's Committee on Mental Retardation. On April 25, 2003, as part of the annual celebration of the Americans with Disabilities Act, President George W. Bush renamed the committee the President's Committee for People with Intellectual Disabilities (PCPID). It

continues to serve in an advisory capacity to the President and the Secretary of Health and Human Services on matters relating to persons with intellectual disabilities.

Much has changed for people with intellectual disabilities since the 1960s due to advances in medicine, technology, research, education, and public understanding. PCPID advises the President on the achievements, continuing needs, and emerging issues in this dynamic field. It evaluates the adequacy of current practices and programs and reviews the impacts of federal agency activities. It also highlights the need for appropriate changes in policy and encourages research, education, services, and supports. PCPID collaborates with other federal agencies and national organizations in convening conferences and forums and disseminating information to the public on issues and accomplishments of people with intellectual disabilities.

PCPID has adopted the goals outlined in President Bush's New Freedom Initiative to recognize and uphold the right of all people with intellectual disabilities to enjoy a quality of life that promotes independence, self-determination, and full participation as productive members of society. The committee builds its work around the initiative's basic categories: expanding educational opportunities, increasing access to technology, improving individual and family support, promoting access and integration into community life, and—the focus of this report—increasing employment and economic independence.

The Committee consists of 21 citizen members appointed by the President and 13 *ex officio* (federal government) members designated by the President. The 13 *ex officio* members are the Secretary of Health and Human Services, Secretary of Education, Secretary of Labor, Secretary of Housing and Urban Development, Secretary of Commerce, Secretary of Transportation, Secretary of Interior, Secretary of Homeland Security, the Attorney General, the President and CEO of the Corporation for National and Community Service, the Chair of the Equal Employment Opportunity Commission, the Chair of the National Council on Disability, and the Commissioner of the Social Security Administration. PCPID is led by an executive director, also appointed by the President, and supported by a team of federal employees.



Members of the President's Committee for People with Intellectual Disabilities meet with President George W. Bush on September 9, 2008

NOTES ON THE DEFINITION OF INTELLECTUAL DISABILITIES AND DATA ASSUMPTIONS:

Research findings are not consistent on the prevalence of intellectual disability in the U.S. population and the numbers of people affected. Estimates range from 1% to 3%, or from three million to nine million people (Fletcher, Loschen, Stavrakaki & First, 2007). Most estimates are closer to 1%.

About 30% of intellectual disabilities are caused by genetic conditions. The remainder are caused by organic conditions. There are more than 750 known genetic causes of intellectual disabilities. Intellectual disabilities can occur as the result of such circumstances as anoxia (lack of oxygen) during delivery, strokes in utero, a brain injury, or as a result of fetal alcohol syndrome (FAS). The American Association on Intellectual and Developmental Disabilities notes three general causal areas: prenatal, perinatal, and postnatal (DM-ID textbook, 2007).

There are several syndromes associated with intellectual disability. While genetic syndromes are individually rare, collectively they contribute significantly to causing intellectual disabilities. For example, based on known incidences of the four genetic syndromes cited below and a conservative estimate that 1% of the general population has an IQ score within the mild to severe range of intellectual disability:

- 1 in 7 people with intellectual disabilities has Down syndrome;
- 1 in 60 people with intellectual disabilities has Fragile X syndrome;
- 1 in 100 people with intellectual disabilities has Prader-Willi syndrome;
- 1 in 200 people with intellectual disabilities has Williams syndrome (Dykens, Hodapp & Finucane, 2002).

According to the National Down Syndrome Society, about 350,000 families in the United States are affected by Down syndrome. About 5,000 children with Down syndrome are born each year. Some experts project that the number of people with Down syndrome will double in the next 10 years

http://www.ndss.org/index.php?option=com_content&view=article&id=47&Itemid=67).

Rates of Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Spectrum Disorders (FASD) range from 0.2 to 1.5 per 1,000 live births in different areas of the United States

<http://www.cdc.gov/ncbddd/fas/fasask.htm#how>).

Executive Summary and Recommendations

Employment brings income, quality of life, and dignity to individuals and families and is an essential part of the American Dream. Yet millions of Americans with intellectual disabilities—the majority—do not work in their own communities.

The problems of unemployment and under-employment of people with intellectual disabilities persist despite decades of research and demonstration initiatives showing that people with intellectual disabilities, including those with syndrome-specific intellectual disabilities, are capable of community-integrated employment. They persist despite the clear intent of more than three decades of state and federal policies confirming the goal of community employment for people with intellectual disabilities.

Today, fewer than one of every five people with intellectual disabilities is engaged in supported employment in their communities—the result of the categorical and short-term nature of many employment programs, poor awareness of individuals' potential, and the inertia caused by decades of institutionalization and other forms of segregation. When people cannot work, they suffer personal indignity, poverty, self-pity, and isolation. They cannot contribute fully to society as household providers, community members, and taxpayers. The nation as a whole then pays severe costs in lost productivity and billions of dollars in publicly financed services.

This report of the President's Committee for People with Intellectual Disabilities describes employment trends and policies, examines barriers to work, and identifies the types of supports that are essential for people with intellectual disabilities to experience the myriad benefits of employment. It shares stories of people with intellectual disabilities who—with the support of their families, public and private programs, and their communities—have found creative ways to contribute to society through work.

The following recommendations represent activities that can help align the *intent* of policies and programs supporting employment of people with intellectual disabilities with the long-sought and worthy *outcome* of community employment:

- 1. Issue a Presidential Call to double the number of people with intellectual disabilities who are working in integrated jobs by 2014. (Current estimates indicate that about 150,000 people with developmental disabilities are engaged in community**

employment, the vast majority of whom have an intellectual disability.)

Convene business, practitioners, providers, foundations, trade associations, government officials, families, and people with intellectual disabilities to craft and enable a plan for rapid expansion of integrated employment outcomes in the community.

2. Create a national public awareness campaign to build a new wave of employment expectations.

Establish and provide resources to create a comprehensive, cross-agency marketing campaign to raise expectations and promote employment outcomes. Such an effort should include people with intellectual disabilities, families, employers, educators, and community leaders.

3. Expand implementation of existing legislation and Federal policy with a specific focus on employment outcomes.

- Provide incentives to states to incorporate employment fully into implementation of the Olmstead decision.
- Develop—with the Social Security Administration, the federal departments of Health and Human Services, Education, and Labor, and the Equal Employment Opportunity Commission—a unified statement emphasizing employment of people with intellectual disabilities.

4. Continue to invest in the New Freedom Initiative.

- Create incentives to States to expand employment outcomes rapidly.
- Establish a task force to study the most successful states, compared to the least successful states in the nation, to create a plan for nationwide improvements in employment outcomes.

5. Create employer incentives and employer demonstrations.

- Convene business leaders and administration officials to develop a plan for specific goals and incentives to the business community for employment outcomes.
- Create tax incentives for large and small businesses, including permanent tax benefits for hiring people with intellectual disabilities.

- Develop dissemination strategies to inform people with intellectual disabilities and their families about such initiatives—reaching out across age, gender, race, and ethnicity.

6. Promote employment of people with intellectual disabilities in the public sector workforce.

- Create an administrative initiative and specific mechanisms within the federal Office of Personnel Management to employ people with intellectual disabilities.
- Convene state government leaders and human resource departments to encourage the creation of state-level priorities and methods for employing people with intellectual disabilities in state and local government structures.
- Develop dissemination strategies to inform people with intellectual disabilities and their families about such initiatives—across age, gender, race, and ethnicity.

7. Promote large-scale demonstration projects based on innovations of the last 10 years.

- Create incentives for states to fully implement a policy to achieve employment outcomes in large geographic areas or across entire states.
- The Centers for Medicare and Medicaid Services, in consultation with the Office of Disability Employment Policy, should fund national customized demonstration projects, with the goal of encouraging expanded, evidence-based use of customized employment strategies.

8. Endorse and expand state Employment First agendas.

- Create fiscal incentives through the federal departments of Labor and Education for states' expansion of employment outcomes.
- Through the Office of Disability Employment Policy, convene stakeholders in the public and private sectors to endorse and facilitate implementation of the Employment First agenda.

9. Promote national and community service for young people, fully integrating young adults with intellectual disabilities in the effort, as a means for transition to adult life.

Work with the Corporation for National and Community Service to expand service projects incorporating young people with intellectual disabilities from all backgrounds.

10. Expand investment in the Individuals with Disabilities Education Improvement Act of 2004 and the Rehabilitation Act's focus on transition plans for all youth with intellectual disabilities including full federal funding of the Act.

- Develop and implement strategies to promote quality, career-focused outcomes in post-secondary education and employment in coordination with the Rehabilitation Services Administration, the Social Security Administration, and the Centers for Medicare and Medicaid Services.
- Ensure that competitive employment is included as a goal in transition plans for all youth with intellectual disabilities.
- Develop dissemination strategies to reinforce to the public sector the communication, information, and physical access standards of the Telecommunications Act of 1996 and the Rehabilitation Act of 2004.

11. Expand investment in the Rehabilitation Services Administration related to funding supports for transition from school to adult life.

Issue U.S. Department of Education guidance encouraging the use of vocational rehabilitation funds to support students with intellectual disabilities in transition to employment and post-secondary education programs, including higher education, from as early as age 14.

12. Increase incentives to work and remove income limits governing benefit programs for people with intellectual disabilities, and promote these incentives.

- Create a federal interagency workgroup to develop a coordinated and comprehensive approach focused on incentives for economic empowerment.
- Work with the Social Security Administration to refine work incentive policies.
- Expand Medicaid “buy-in” provisions, which allow states to expand program benefits to workers with disabilities whose incomes would otherwise make them ineligible, thus protecting health care benefits.
- Provide tax incentives, to individuals and families, for employment support services such as personal assistance, transportation, and

assistive technology.

- Establish public-private partnerships to support people with intellectual disabilities during transition from school to adult life.

13. Refocus existing resources to promote integrated employment.

- Work with the federal Centers for Medicare and Medicaid Services related to Medicaid waivers to promote community outcomes rather than services in segregated settings.
- Develop and facilitate implementation of educational programs that are culturally sensitive and likely to increase positive outcomes in the lives of people with intellectual disabilities.

Introduction

This 2009 Report to the President and its recommendations address two closely related and persistent problems: high unemployment and lack of economic freedom for citizens with intellectual disabilities. We make the argument that people with intellectual disabilities are fully capable of working successfully in integrated community settings, despite a history of unemployment and segregation from the mainstream of American economic life. We explore the argument in the following sequence:

- I. The **Current Employment Status** and unrealized potential of people with intellectual disabilities,
- II. The **Evolving Policy and Legal Framework** for employment that clearly establishes a framework of rights,
- III. **Employment Practices** that show promise and may contribute to the goal of full employment for people with intellectual disabilities,
- IV. The practical steps to **Building an Education, a Resume, and Experience**, and
- V. The **Family and Systemic Supports** that make employment outcomes possible.

We begin each section with a discussion of the relevant issues and include examples, where appropriate, of recent experiences of people with intellectual disabilities in the workforce. In each section, we also offer recommendations to support the rapid expansion of employment outcomes and economic freedom for people with intellectual disabilities.

I Current Employment Status

MARGINALIZED IN THE WORKFORCE

The American work ethic is at the heart of our communities and our society. America relies on the individual and unique contributions of citizens from every walk of life, of all ages, of every color, race, and nation of origin. The lives of nearly every American are wrapped in the contributions made to family and community. Employment brings not just income and quality of life to individuals and families—it brings dignity.

This part of the American Dream does not belong to the vast majority of people with intellectual disabilities in the United States, despite the talents, capabilities, and commitment to work that they have to offer. Employment data from many sources paint a picture of intolerable levels of unemployment and underemployment.

The U.S. Department of Labor reports that about 79% of people *without* disabilities participate in the nation's workforce. Compared with this figure, the percentage of workers among people *with* disabilities is extremely disappointing. The Harris Poll has tracked employment trends of adults with disabilities—including intellectual disabilities—since 1986. The poll data reveal that the percentage of adults with disabilities ages 65 and younger who are working remained “virtually unchanged”—at 32%—during 1986 to 2000. This figure is particularly discouraging given the passage of several important policy initiatives during this period, including the Americans with Disabilities Act in 1990 (Harris Interactive, http://www.harrisinteractive.com/harris_poll/index.asp?PID=121).

Looking specifically at employment data for people with intellectual disabilities—the numbers are even worse. As revealed in *the 2008 State of the States in Developmental Disabilities*, only 22% of people with intellectual or developmental disabilities participated in supported employment programs in fiscal year 2006. The five states with the highest percentages are Oklahoma (77%), Washington (61%), Connecticut (51%), Vermont—the first state to eliminate segregated day workshop settings for people with intellectual disabilities (48%)—and Louisiana (45%). The five states with the lowest percentages are Arkansas (2%), Alabama (5%), Hawaii (8%), Missouri (9%), and Kansas (10%) (Braddock, Hemp, & Rizzolo, 2008).

COSTS OF UNEMPLOYMENT AND UNDER-EMPLOYMENT

One way to view the marginalization of millions of American workers is in terms of lost productivity, wages not earned, and taxes not paid.

Another is to examine the cost of supports that are necessary because these potential workers are not earning wages.

Complete and current numbers for such costs are not available. A 1999 report prepared for Florida's Able Trust calculated the estimated cost of unemployment for people with all disabilities at about \$8 billion annually (Hemenway & Rohani, 1999). This estimate—a conservative one that would be considerably higher if stated in terms of 2008 dollars—included more than \$3 billion annually in lost productivity and nearly \$4 billion in lost contributions to Social Security and other government programs. Calculated on a national scale, the cost of unemployment of people with intellectual disability is enormous—to them, their families, and to our society.

The nation's current investment in quality employment outcomes is a small share of spending on programs for people with intellectual disabilities: only 2% of the nearly \$44 billion in spending for all services for people with intellectual disabilities, compared with 16% spent on public and private institutions (Braddock, 2008).

While the lost productivity and costs associated with publicly financed support services can be roughly calculated, the cost in loss of dignity and quality of life is incalculable. As with all people who wish to work and cannot, people with intellectual disabilities who lack employment may experience isolation from social networks, dependence, low self-esteem, and persistent poverty.

PROMISING DIRECTIONS IN RESEARCH

People with intellectual disabilities have the same work ethic as other citizens. Research and demonstration initiatives nationwide and internationally clearly show that people with intellectual disabilities, including those with syndrome-specific intellectual disabilities, are capable of integrated employment in the community.

People with intellectual disabilities have demonstrated their abilities, competence and desire to work and contribute to their families, communities, and society. They work successfully in venues ranging from their own small businesses, to small and large companies, and to jobs in local, state, and federal government agencies.

Research results showing the potential of people with intellectual disabilities come from a growing body of applied, practical research in typical community settings. “Basic” research in defined settings is later translated into applied research in community settings, and the results are used to develop useful interventions and approaches to achieve positive employment outcomes. An important part of the research base showing the capabilities and potential of people with intellectual disabilities comes from community businesses and job settings.

Research findings emphasize individually tailored strategies and supports. Applied research results demonstrate that successful strategies for promoting employment outcomes are built on understanding each individual's talents and abilities and on understanding the challenges and support needs specific to the person.

One approach emerging from research is focused on adapting environments. Research shows that the environments in which people work play a more important role in promoting employment than do personal characteristics of the person, including level of intelligence. For example, an issue for some individuals with genetic syndromes is that behaviors may interfere with job performance as much as, if not more than, learning difficulties. The use of positive behavior supports and attention to environmental factors can improve the probability of long-term job success. For a particular person, a noisy job environment may act as a trigger for unsuitable behavior. A great deal of forced eye contact could result in distractions and poor work performance.

Preparing the environment, and working with co-workers about a person's support needs, can support long-term success on the job. Research provides a base of knowledge for crafting individualized supports, including knowledge about supports for individuals with genetic syndromes that result in intellectual disability.

To promote the goal of increasing employment for transition-age youth with disabilities, the Social Security Administration (SSA) created the Youth Transition Demonstration (YTD) to assist youth with disabilities to transition from school successfully, which may include post-secondary education, to employment and economic self-sufficiency.

Youth participating in the project will be followed for at least four years to determine whether interventions led to increased earnings or increased enrollment in post-secondary education. SSA is testing the effectiveness of enhanced coordination of services for youth with disabilities and altering certain Supplemental Security Income rules as an incentive to encourage beneficiaries to initiate work, increase their employment, and increase earnings.

During the past decade, people with intellectual disabilities have become increasingly involved in the design and conduct of this research—known as “participatory action research.” The focus is on involving people with intellectual disabilities in all phases of applied research to improve the quality of research activities and extend the reach of their findings into everyday life settings.

INCREASING AWARENESS

People with intellectual disabilities have become more vocal in the discussion of goals for employment. They do not want to live in poverty and desire the same levels of discretionary income that other citizens expect. Self-advocates make clear their expectations of a right to a job in the community, at full wages. For example, Self Advocates Becoming Empowered! (SABE, 2008) is calling for an increase in community employment at full wages and the closure of segregated workshop settings. SABE is a national self-advocacy organization created and run by people with intellectual and developmental disabilities.

The involvement of people with intellectual disabilities is critical as an advocacy voice for meaningful employment as well as in the conduct of research on improving employment outcomes. Despite some success, the public perception of people with intellectual disabilities is still largely an image of *inability*. Instead of seeing people with intellectual disabilities in valued community work roles, the public too often sees people with intellectual disabilities segregated in large homes, riding agency buses and vans, or working in sheltered workshops (typically referred to as community rehabilitation programs, or CRPs). Too often, when people with intellectual disabilities are seen in the community, they are seen in groups, physically present in the community but rarely interacting in typical ways with others (DiLeo, 2007). Hence, this perception assumes that gainful employment is not a possibility, promoting an image of charity rather than contribution.

SUMMARY

Work is central to the American Dream and is instrumental to achieving lives of purpose and dignity. Research and demonstration initiatives have consistently shown that people with intellectual disabilities are capable of integrated employment in the community. Yet today, only 22% of people with intellectual disabilities participate in supported employment programs in their communities compared with 79% of people who participate in the U.S. workforce. This disappointing reality costs the nation dearly in lost productivity as well as billions in publicly financed services.

RECOMMENDATIONS

- 1. Issue a Presidential Call to double the number of people with intellectual disabilities who are working in integrated jobs by 2014. (Current estimates indicate that about 150,000 people with developmental disabilities are engaged in community employment, the vast majority of whom have an intellectual disability).**

Convene business, practitioners, providers, foundations, trade associations, government officials, families, and people with intellectual disabilities to craft and enable a plan for rapid expansion of integrated employment outcomes in the community.

- 2. Create a national public awareness campaign to build a new wave of employment expectations.**

Establish and provide resources to create a comprehensive, cross-agency marketing campaign to raise expectations and promote employment outcomes. Such an effort should include people with intellectual disabilities, families, employers, educators, and community leaders.

II Evolving Policy and Legal Framework

POLICY DIRECTION

Employment rights for people with intellectual disabilities have been fully anchored in policy and law for more than a quarter century. Both embody an increasing emphasis on independence, productivity, and integration. Yet as noted in the previous chapter, barely one of every five people with intellectual disabilities is employed in their communities. Despite the clear policy intention, the goal of community employment for people with intellectual disabilities continues to face persistent barriers, including growing pressure on public resources, the categorical and short-term nature of many programs, poor awareness of individuals' potential, and perhaps most significantly, the inertia caused by decades of institutionalization and other forms of segregation.

This section relies heavily on Paul Wehman's description of the policy and legal framework of employment for people with disabilities published in Chapter 8 of *National Goals and Research for People with Intellectual and Developmental Disabilities* (Wehman, Mank, Rogan, Luna, Kregel, Kiernan, et al, 2005). This policy and legal section describes the triangulating themes from the New Freedom Initiative, the Rehabilitation Act, the Developmental Disabilities Assistance and Bill of Rights Act, the Americans with Disabilities Act, the Workforce Investment Act, the Individuals with Disabilities Education Act, the Ticket to Work and Work Incentives Improvement Act, and the U.S. Supreme Court's Olmstead decision.

- **The New Freedom Initiative**

President Bush announced the New Freedom Initiative on February 1, 2001, as part of a nationwide effort to remove barriers to community living for people with disabilities. The initiative is a clear plan to ensure that all Americans have the opportunity to learn and develop skills, engage in productive work, make choices about their daily lives, and participate fully in community life. Several of its proposals affect federal policy as implemented by the U.S. Department of Health and Human Services, including promoting full access to community living through swift implementation of *Olmstead v. L.C. and E.W.* (see page 18 hereof) and integrating Americans with disabilities into the workforce through swift implementation of the Ticket to Work and Work Incentives Improvement Act of 1999 (see page 18 hereof).

- **The Rehabilitation Act**

The Rehabilitation Act of 1973 and its amendments support local

authorities to serve the employment needs of people with disabilities and focus on their transition from secondary education to adult life. It is the primary employment support resource for adults with disabilities. The 1998 amendments provide federal dollars, matched by state dollars, to all states to give people with developmental disabilities the opportunity to obtain employment and independent living assistance as needed. The vocational rehabilitation system no longer recognizes or pays for an outcome of segregated employment.

- **The Developmental Disabilities Act**

With the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) of 2000, Congress observed that national policy for people with disabilities should be characterized by independence, productivity, and integration. This legislation built on the 1984 Developmental Disabilities Act, which for the first time focused on employment as an important hallmark of services for people with developmental disabilities. In fact, supported employment for people with developmental disabilities was first defined in the 1984 law.

- **The Americans with Disabilities Act and Amendments**

Congress intended the Americans with Disabilities Act (ADA) of 1990 to end discrimination toward people with disabilities throughout society and encourage good jobs with adequate incomes. The ADA reflects the rights of persons with disabilities to be in the community. A year after its passage, a comprehensive set of federal regulations provided specific guidelines regarding accessibility, nondiscrimination, and greater access to workplaces, community facilities, public transportation, and telecommunications. Employment is a central focus of the ADA. In 2008, the ADA Amendments Act clarified the definition of disability and the intention of the Act to serve as a national mandate for elimination of discrimination, including discrimination in employment.

- **The Workforce Investment Act**

The Workforce Investment Act (WIA) of 1998 is the first major reform of the nation's job training system since 1982. With its passage, Congress established a requirement that states and localities fully include and provide for appropriate accommodation for persons with disabilities. The WIA streamlined services through a one-stop employment service delivery system, empowered job seekers through information and access to training resources through individual training accounts, and improved youth programs.

- **The Individuals with Disabilities Education Improvement Act of 2004**

The Individuals with Disabilities Education Act, as amended by the Individuals with Disabilities Education Improvement Act of 2004 (IDEIA), establishes clear expectations that are focused on enhancing the academic and functional achievement of children with disabilities, including children with intellectual disabilities, to facilitate the movement from school to post-school activities.

These activities would include post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation.

- **The Ticket to Work and Work Incentives Improvement Act (TWWIIA)**

The Ticket to Work Program provides adults with disabilities ages 18-64 who are receiving Social Security benefits more choices for receiving employment services. Under this program, the Social Security Administration issues tickets to eligible beneficiaries who, in turn, may choose to assign those tickets to an Employment Network (EN) of their choice to obtain employment services, vocational rehabilitation services, or other support services necessary to achieve a vocational goal. If they accept the ticket, the EN will coordinate and provide appropriate services to help the beneficiary find and maintain employment.

Many persons with disabilities fear that, by taking any job that paid even a minimal income, they would lose their cash and medical benefits, which are vital to maintaining their lives. The TWWIIA provides incentives so that people with disabilities who are pursuing a vocational goal can keep their benefits, including medical coverage, while they prepare for work and for an extended period of time after beginning work. The TWWIIA also makes it easier for individuals who try to work, but are not successful, to start getting benefits again. By expanding the range of employment service providers and by creating incentives to make it possible for individuals to establish themselves in a job or career without risking their benefits, the TWWIIA ushered in a dramatic new era of work opportunities for persons with disabilities.

- **Olmstead v. L.C. and E.W.**

The U.S. Supreme Court in 1999 ruled that public agencies are required to provide services to people with disabilities “in the most integrated setting appropriate to the needs.” The court ruled that this “integration mandate” specifically applies to persons living in

institutional settings and is more recently being discussed in application to the right to community employment rather than segregated day settings.

SUMMARY

The clear thrust of federal policy for people with intellectual disabilities during the past 40 years has been to promote employment outcomes and independent living. Legislation has addressed school-to-work transition, non-discrimination in the workplace, protection of health benefits provided through publicly insured programs, and service provision in the most inclusive settings possible. This policy and legislative direction exists alongside the facts about segregation and unemployment of people with intellectual disabilities.

Despite the amount of legislation passed to promote employment, much work remains to be done to ensure implementation and the needed improvements of employment rates for persons with intellectual disabilities. The policy emphasis in the next decade should be geared toward full implementation of these laws and guidelines.

RECOMMENDATIONS

3. Expand implementation of existing federal policy with a specific focus on employment outcomes.

- Provide incentives to states to incorporate employment fully into the implementation of the Olmstead decision.
- Develop—with the Social Security Administration and the Departments of Health and Human Services, Education, and Labor—a unified statement emphasizing employment of people with intellectual disabilities.

4. Continue to invest in the New Freedom Initiative.

- Continue investment in the New Freedom Initiative, creating incentives to states to rapidly expand employment outcomes.
- Establish a task force to study the most successful states, compared to the least successful states in the nation, in order to create a plan for nationwide improvements in employment outcomes.

III Employment Practices

FOUR AMERICAN WORKERS

*In 2001, a staff member of the Oregon Health Sciences University Center on Self-Determination approached Michael Powell, owner of the legendary Powell's "City of Books" in Portland, Oregon. **Andy**—who speaks with facial expressions and movement but not words—wanted a job working with books. He had volunteered at his local community library and his high school library. Andy has since experienced his ideal job, receiving books into the store database and scanning them for the store inventory. He is held to the same expectations as his co-workers, and as with all employees, is required to adhere to company policies....Says Powell of Andy's contribution: "His dedication and diligence serve as a reminder that a job is more than just a paycheck....Andy has been an inspiration to all of us."*

*Soon after **Dan** was born in 1969 with Down syndrome, a doctor recommended withholding a lifesaving medical procedure. When his parents refused, the doctor advised placement in a state institution. But Dan's family had other plans. They mobilized their strong family unit and support from teachers, job coaches, and counselors, as well as Dan's own strong work ethic. In addition to creating an environment where the people in Dan's life learned to see his abilities, this effort led to a job in the Microsoft mail room in Bellevue, Washington. Dan loved his work and was the fastest and most accurate mail sorter in the company. He worked at Microsoft for more than 14 years, until only five days before his death from heart disease at age 36. On the day Dan died, Microsoft flew its flag at half-staff.*

***Marty** was diagnosed with mild intellectual disability, but the disability that seemed to present the most formidable barrier between him and others was a severe hearing loss that made it difficult for him to understand and communicate. While participating in a pre-vocational day program following high school, Marty was recommended for a job at the Scotch N'Sirloin restaurant in Buffalo, New York. The skills demanded in the job were a perfect fit. Marty also found a supporter in the restaurant's general manager. He had grown-up with a friend who was deaf and became instrumental in modeling communications so coworkers could understand Marty and*

get to know him. Today—20 years later—Marty still works at the restaurant and is known for being an extrovert who is always telling stories and relating events.

***Casey** is a citizen member of the President’s Committee for People with Intellectual Disabilities, an Eagle Scout, and an Honorary Deputy Sheriff in his home town of North Fort Meyers, Florida. He started working while still in high school with a job at Daddy Dee’s Ice Cream Parlor and at a local Gap store. Since graduation, he has worked as a clerical assistant for the Lee County Justice Center and has attended community college. In his personal statement to employers, Casey expresses his desire to be “an asset to your organization because I am a dedicated employee. It is important to me to be a productive and loyal member of a team and to do my best for you. I have very good people skills. I am outgoing, friendly, respectful, mannerly, and upbeat. I can perform repetitive tasks with satisfaction. But I welcome new responsibilities, and once I learn them, I perform them independently.” Because employers and co-workers have focused on his qualities, strengths, and loyalty—and not on his Down syndrome—he has proudly attained his goal of becoming an independent, productive, tax-paying citizen.*

Andy, Dan, Marty, and Casey were fortunate to seek employment in a period when many employers, large and small, are thinking in an open and creative way about the capabilities and contributions of people with intellectual disabilities in the workforce. This approach capitalizes on the strengths of people with intellectual disabilities and brings new possibilities for reciprocal alliances with the business community. A federal agency, the Department of Labor Office of Disability Employment Policy (ODEP) has, since 2001, supported this direction by developing and promoting evidence-based disability employment policies and practices. Its vision is to create workplaces where people with disabilities have “unlimited employment opportunities.” ODEP promotes customized employment, self-direction, and self-sufficiency (Griffin, Hammis, Geary & Sullivan, 2008; Elinson, Frey, Li, Palan & Horne, 2008).

COMING INTO THE MAINSTREAM

From the onset of the Industrial Revolution in the 1830s to the advent of the mini-computer in the 1960s, “standardization” drove growth in the American economy. This pattern pushed to the margins anyone outside the mainstream, including people with intellectual disabilities. But as our society has undergone an economic paradigm shift—from an

industrial model to one centered on information, technology, and networks—we have developed a more complex understanding of the wide range of intellectual disabilities and of capacities for personal development and meaningful work.

People with intellectual disabilities are productive, loyal employees when they have employment opportunities suited to their capabilities and interests, much as those without a label of disabilities. It is also true that people with intellectual disabilities today excel in many jobs that were once considered closed to them. The questions public policy makers and employers ask in providing employment opportunities for people with intellectual disabilities are changing from “what accommodations do we provide?” to “what investments do we make to help these employees be most successful?” In other words, they address success regarding *all* employees.

As employers discover the value of the contributions people with intellectual disabilities can bring to the workforce, they are showing an eagerness to customize opportunities. People with intellectual disabilities are also beginning to create and run their own small businesses. New employment enhancements and supports are helping people stay in their jobs. Technology solutions now make it possible for people with physical, sensory, and intellectual disabilities to perform valued work in new ways. All of these developments have the potential to break through the painful reality of unemployment and underemployment of people with intellectual disabilities—to the great benefit of all who participate in America’s economic life (Mank, 2007).

Services provided by programs such as the Job Accommodation Network (JAN), funded by ODEP, help employers determine practical, low-cost, and sometimes no-cost reasonable accommodations to help support workers with intellectual and other disabilities (<http://www.jan.wvu.edu>).

A RANGE OF EMPLOYERS

Walgreens. Starbucks. The Boeing Co. Wal-Mart Stores, Inc. Microsoft Corp. Highmark, Inc. WellPoint Inc. CVS/Pharmacy. These large **corporations** and hundreds more successfully employ people with intellectual disabilities. These opportunities are emerging as a result of new employer relationships (Luecking, Fabian & Tilson 2004, Luecking, 2008).

***Julia**, who was born with Down syndrome, is one of more than a hundred employees of the Walgreens Distribution Center in Anderson, South Carolina, who has some type of physical or cognitive disability. "I've found what I want," she says of her full-time position. The company announced in 2007 that it intended to fill about a third of the anticipated 800 jobs at the new center with people with disabilities. As reported on ABC news, the outreach to people with disabilities is encouraged by Randy Lewis, the company's senior vice president of distribution and logistics, whose son has autism. In Anderson County, the rate of employment for people with disabilities is close to 90%. The policy at the Anderson distribution center is being duplicated at a network of Walgreens distribution centers across the country.*

***Courtney** works for a Starbucks in Seattle with a job coach who signs, assists her in learning new tasks, and helps her find her way around the store. Courtney washes dishes, works at the condiment bar, keeps the lobby clean, and particularly enjoys grinding coffee for COW—the coffee of the week promotion. As Starbucks CEO Howard Schultz explains, "We're in a position where we have to hire a lot of people. And we've benefited from hiring people with certain disabilities who have added value to the company and have done a great job....This program has generated so much good will inside our company and with our customers. Working alongside people with disabilities benefits the people working next to them. They learn something about life, about other human beings. I think it has opened up a whole new world for us."*

The Boeing Co. discovered the potential and contributions of people with intellectual disabilities more than 20 years ago, and the company has its own department designed to bring people with disabilities into its workforce.

Wal-Mart hires people with intellectual disabilities at its distribution centers and in other operations and is sharing its experience with other corporations across the United States.

People with intellectual disabilities are also being welcomed into the workplace by **small businesses**:

***Jesse** has always had trouble staying still—a characteristic of his autism. Fortunately, he has outlets for his restive nature in the myriad jobs that need doing on Tide Mill Farm on Maine's magnificent Cobscook Bay. Jesse's family has worked the farm for nine generations, most recently raising organic chickens, cows, pigs, and vegetables. Jesse carries grain and water in a utility vehicle to chickens and pigs. He wraps huge silage bales for storage, and he splits and hauls firewood to warm the*

greenhouse. Jesse is restoring a 1953 Studebaker pick-up truck like one that was used on the farm in the 1960s. He owns his own home on the family spread. And he still finds time to volunteer for his local fire department.

In the **non-profit sector**, Cincinnati's Children's Hospital Medical Center launched a highly successful strategy in Project SEARCH, an initiative originally developed to recruit people with developmental disabilities for jobs stocking supplies and delivering mail across the hospital's large campus. The initiative expanded quickly: the hospital was soon working with several agencies and managing a team of job coaches. Several other health care facilities came on board, along with local businesses including banks and retail stores. Program Director J. Erin Riehle reports, "Our approach creates internal advocates for disability employment." Project Search is now national in scale and is a strategy adopted in a number of states (<http://www.cincinnatichildrens.org/svc/alpha/p/search/>).

Public sector agencies were early to welcome workers with intellectual disabilities:

*When **Michelle** graduated from high school in 2000, she was already settled into a job she loved at the Oregon State Department of Human Services Office of Disability Services. At first shy and "frightened about work," she relied on guidance from a job coach and coworkers who were eager to carve-out tasks and help her organize her workday by breaking down complex tasks into manageable pieces and tracking them with checklists. Her job for the state has expanded and now involves compiling complex copying, faxing, and mailing projects—some involving individual mailings of hundreds of pieces. She works full-time, lives independently, has an active social life, and participates in the Special Olympics.*

Public sector initiatives have proven effective in the employment of individuals with a range of intellectual disabilities. For example, Mank, O'Neill and Jensen (1998) report outcomes of employment in a metropolitan county government that were nearly double the employment outcomes nationally for people with intellectual disabilities.

DISCOVERING ABILITIES

Today a range of services is available to help job seekers who have intellectual disabilities discover their strengths and the ways they can be mobilized on behalf of employers' goals. This process and assessment typically build on individual life experiences, interests, and preferences. Such "person-centered planning" creates job situations, when the

policies of the past usually tried to match people with intellectual disabilities into any jobs that were available. This process of “discovery” has been well developed in recent years and is being adopted nationwide (Callahan & Condon, 2007).

Closely related to person-centered planning is customized employment, the goal of which is to find opportunities that meet the individual needs of both job-seekers and employers. The goal of this approach is to individualize the relationship between job seekers and employers so that it meets the needs of both.

EMPLOYMENT SUPPORTS

Often people with intellectual disabilities require some type of employment supports—the formal and informal activities at any job that enable people to be successful in their work. Supports can be internal and external to the job. They should make use of what is already in the workplace or can be adapted there. External supports—instruction, transportation, etc.—can be added to the work environment as needed.

Assistive technology solutions for creating and supporting quality employment are emerging rapidly (Davies, 2008). Cognitive and rehabilitation technologies and software restore or improve memory and cognitive functioning. Personalized icons and pictures allow for easier sequencing of work tasks and provide reminders. Small personal digital assistants and “smart phones” allow individuals with intellectual disabilities to follow and stay on schedules. Simplified formats provide for ease of communication and use of email and the internet. Virtual assistants, along with global positioning systems, allow use of public transportation. An individual can use such technology at work, at home, and in any other environment.

Technology enhances social skills training. Prompting technology with these small devices encourages independent work performance. Many of these advances in technology exist in small devices similar to the ubiquitous presence of iPods, cell phones, smart phones, and personal digital assistants. These devices are widely available and while they may be specialized in their use, they appear no different from the devices used by the majority of Americans in their day-to-day lives.

The successes and benefits of these approaches are well-established in research and in demonstration projects. Further, when assistance and support is provided to employees with intellectual disabilities, tax revenue rises and society benefits as well.

SELF-EMPLOYMENT

The federal Office of Disability Employment Policy (<http://www.dol.gov/odep/>) considers self-employment to be an employment alternative for individuals seeking a new or better career. The more than 20 million small businesses in the United States collectively are the largest employers in the nation. Self-employment is the ultimate customizing of a job, based on passion for a particular mission as well as personal interests, abilities, and skills.

Today, many job seekers with intellectual disabilities are discovering that creating one's own business means total flexibility to meet career aspirations and financial goals (Griffin & Hammis, 2003). People who are self-employed have increased latitude to define their working hours, types of supports, and financial goals. For people with intellectual disabilities—as well as those who launch their own businesses—success in self-employment requires supports from people and structures that can assist in business and financial planning.

*When **Logan** was 16, she suffered a heart attack and fell into a coma. When she woke up, she couldn't hold up her head, talk, or swallow, and she had to relearn the most basic skills. She had always loved clothes, and when she returned home from the hospital after seven months, she decided the world needed a magazine for young women, like her, with disabilities. Her motto: "Do your makeup still. Do your hair still. Keep living!" To build her business, Logan learned to project her voice and speak more clearly during presentations about the magazine. She learned to complete order forms and schedule meetings using a day planner, and she worked hard at writing clearly. Today she and her mother, Laurie, run Logan Magazine—a publication that features fashion, articles on "cheap chic," inspirational stories, and tools for living such as cosmetics that work for women with fine motor impairments.*

***Daniel** always liked using tools. Eight years ago, his high school suggested he use his skills to build houses for mountain blue birds because recent wildfires that had swept through Washington's Leavenworth Valley had driven nearly all of them away. An expert on mountain blue birds came to school, and Daniel's whole class became involved in the project. In the eight years since, Daniel has built more than 1,000 bird houses, which hang throughout the valley. He builds the*

houses at home and in the community at the annual Leavenworth Bird Festival, doing more than 90% of the work himself. The National Park Service is now buying his birdhouses. Daniel, who can create four of the houses a day, is planning to expand to building houses for ducks and bats.

STATE INITIATIVES

Several states have committed to an Employment First philosophy for programs for people with intellectual disabilities—recognizing employment as the preferred outcome for supports and services. For example, Minnesota convened stakeholders to establish a priority for more rapid development of supported and customized employment (Minnesota Department of Human Services, 2007). Indiana launched Vision 2010, a policy emphasizing integrated employment outcomes over segregated services and unemployment. Washington established the Working Age Adult Policy, reflecting the expectation that people with developmental and intellectual disabilities will work in community settings or be on a pathway toward community employment (Washington State Division of Developmental Disabilities, 2006).

The expanding commitment to employment occurring in states is reinforced by the work of national organizations. For example, the Association for Persons in Supported Employment (APSE): The Network on Employment—a membership organization that works to improve integrated employment opportunities, services, and outcomes for people with disabilities—helped sponsor a “change forum” in 2008 in Kansas City to encourage and support state expansion of integrated employment programs.

These efforts, while not yet widespread, are built on the growing expectation of employment and economic freedom by people with disabilities. They recognize that full participation in the nation’s workforce is now more possible than at any time in history.

RECOMMENDATIONS

5. Create employer incentives and employer demonstrations.

- Convene business leaders and administration officials to develop a plan for specific goals and incentives to the business community for employment outcomes.
- Create tax incentives for large and small businesses, including a permanent tax credit for hiring people with intellectual disabilities.

- Develop dissemination strategies to inform people with intellectual disabilities and their families about such initiatives—reaching out across age, gender, race, and ethnicity.

6. Promote employment of people with intellectual disabilities in the public sector workforce.

- Create an administrative initiative and specific mechanisms within the federal Office of Personnel Management to employ people with intellectual disabilities.
- Convene state government leaders and human resource departments to encourage creation of state-level priorities and methods for employing people with intellectual disabilities in state and local government structures.
- Develop dissemination strategies to inform people with intellectual disabilities and their families about such initiatives—across age, gender, race, and ethnicity.

7. Promote large-scale demonstration projects based on innovations of the last 10 years.

- Create incentives for states to fully implement a policy to achieve employment outcomes in large geographic areas or across entire states.
- The Centers for Medicare and Medicaid Services, in consultation with the Office of Disability Employment Policy, should fund national customized demonstration projects, with the goal of encouraging expanded, evidence-based use of customized employment strategies.

8. Endorse and expand state Employment First agendas.

- Create fiscal incentives through the Federal Departments of Labor and Education for states' expansion of employment outcomes.
- Through the Office of Disability Employment Policy, convene stakeholders in the public and private sectors to endorse and facilitate implementation of the Employment First agenda.

IV Building an Education, a Resume, and Experience

Business leadership and corporate initiatives, customized and supported employment, business ownerships, and the emergence of assistive technologies all provide the tools for inviting the contributions of people with intellectual disabilities and for creating vastly improved employment outcomes. Individuals with intellectual disabilities are ready to work when appropriate technological and other supports are provided as needed, to facilitate ongoing employment, career success, and economic self-sufficiency.

Evidence-based research has confirmed that the benefits of employment— income, dignity, socialization, and independence—are conferred on all workers, including those with intellectual disabilities. The ways people *become* and *remain* employed are common among all population groups. It is also critical, at an individual level, to promote the building of an education, a resume, and work experience for individuals to become gainfully employed. People with intellectual disabilities need opportunities for career development through access to the same “resume-building” experiences as others in the workforce. These strategies include: promoting successful transition from school to employment (Hartwig & Sitlington, 2008); providing opportunities for internships while still in school (Getzel & Briel, 2008); promoting post-secondary education (Blumberg, Daley & Yau, 2008); and use of volunteer opportunities to build experience (Bazilio-Bellegarde & Brandenburg, 2008).

TRANSITION FROM SCHOOL TO EMPLOYMENT

Education that will promote a valued role in society and in the workplace is essential for long-term success, regardless of career goals. Successful transition programs for people with intellectual disabilities have emerged in many states across the country. They include such elements as employment services (job-finding and placement), vocational and on-the-job training, post-secondary and other education services, counseling, and transportation. The most effective transition programs emphasize a forward-looking and practical approach to a curriculum and experiences that lead to employment.

Leaving high school is an important time for anyone—no less so for young people, up to age 21, who have intellectual disabilities.

Noah was attending high school in Orchard Park, New York, when he had the good fortune to connect with a school-to-work program offered by a local human services agency, People Inc. Diagnosed with Asperger's syndrome and other intellectual disabilities, Noah benefited from a range of agency services that nurtured him and encouraged his independence. While he was still in school, the staff worked with him five days a week, exploring careers and touring local businesses. After Noah graduated in 2001, the agency supported his participation in internships at a local toy store and a hotel, and it helped him attend classes at local community colleges. In 2007, Noah found work as a security guard—a job in which he has done well with the help of an employment specialist. Today he enjoys living in his own apartment.

Successful transition is rooted first in a belief that an individual with an intellectual disability can be employed. As such, the skills of self-direction and self-advocacy and planning must be incorporated throughout every student's curriculum. Schools must emphasize employment choices and career development for their transition-age youth (broadly defined as ages 16-24) as well as provide work experiences.

Research shows that one of the best predictors of employment beyond the school years is the number and variety of work experiences while in school. Indeed, some transition programs are now focused on ensuring that the last few years of special education focus entirely on job and community experience and practical skill-building if employment is the immediate goal after high school rather than post-secondary education.

Darnell, an 18-year-old student with developmental disabilities, is employed in the Mississippi Model Youth Transition Innovation, part of the Social Security Administration's Youth Transition Demonstration Project. Darnell and his mother wanted him to have an opportunity to work as other students his age, contributing to the community. While his teachers and some of his family were doubtful of his likelihood of success in competitive employment, Darnell proved he is capable of independent employment by customizing his job. He has been employed as a customer service associate by a local retail shoe store since November 2004. His duties are to label oversize shoe boxes so customers can find them on the shelves more easily. He also maintains display cases and does general store maintenance. His duties have expanded to greeting and assisting customers. During the school year, he works three hours a day, four days a week. He returns to school each day to share with his classmates and teachers his new independence.

INTERNSHIPS

Students with and without disabilities benefit from the opportunities to explore business and industry while they are still in school. Internships create opportunities for students to engage in several kinds of employment to build a resume of work experiences, discover what they do best, and make informed choices about the kind of work and work situations they want to pursue in a career.

***Sarah** has achieved a goal that would be the envy of many young people: She turned her unpaid internship at a place where she loved to work to a paid job that was waiting for her when she graduated from high school. She first connected to her employer, Recreation Equipment Inc. (REI), through the Lake Washington School District Transition Academy in suburban Seattle. The next summer, the King County Developmental Disability Division School to Work Program found her a paid internship at REI, which led to a paid, part-time job. During this time, Sarah progressed from cleaning changing rooms to working in merchandizing. A picture of her proudly holding her first paycheck ran in a local newspaper.*

POST-SECONDARY EDUCATION

Post-secondary education has not often been offered to individuals with intellectual disabilities, even though it is a sound choice for some. Citing 2004 data from the U.S. Department of Education, the National Council on Disability reports that, of more than 15 million students enrolled in secondary or postsecondary vocational and technical education courses nationwide, barely one million were individuals with disabilities (NCD, 2008). Research on employment indicates that youth with disabilities who receive post-secondary education are more likely to be competitively employed and have higher earnings than peers who do not have post-secondary education. According to one study, 139 two- or four-year institutions of higher learning in 36 states provide some type of post-secondary programs for students with intellectual disabilities (ThinkCollege.net).

Several states have begun to explore ways to make post-secondary education available. For example, the College of New Jersey offers education to people with intellectual disabilities through peer mentors and individually tailored coursework. Mentors model social and academic engagement and provide other academic supports. Coursework might include career planning, assistive technology, social skills, health and wellness, and training in new technologies, along with internships in employment settings. The Higher Education Opportunity

Act of 2008 provides students with intellectual disabilities opportunities that can create pathways to new and non-traditional employment.

Zach, who has Down syndrome, could boast of many achievements by the time he turned 19: climbing the Great Wall of China, coaching hockey games, and being king of his prom. His busy life has recently entered a new phase: attendance at a special-needs program at Elgin Community College in Illinois. He will continue to live at home while he pursues the two-year program, but after graduation, he may attend another college and live on campus. His mother gives credit to “out-of-the-box” thinkers on Zach’s high school faculty for some of the success he has had in school. Sometimes, all that was needed was a simple intervention, such as putting his school work into a larger font.

VOLUNTEERING

Volunteering to be of service in one’s community can be a tool to build a resume and skills, a way to test how individual interests and abilities can be applied in the workplace, and an opportunity to discover one’s own preferences for various kinds of work. It can confer social, emotional, and even physical benefits, consequently bringing great personal fulfillment. Within a career development context, volunteering time and talents through community service is but one of a series of important steps that must be taken on the path toward economic independence. Particularly when volunteerism is combined with service learning, new skill acquisition is likely, thereby making people more competitive in the workplace.

The Corporation for National and Community Service (CNCS), a federal agency, is one exemplary mechanism for promoting and facilitating volunteerism in communities of every size across the country through grant programs and partnerships with national, state, and local organizations. CNCS promotes countless ways in which ALL Americans of all backgrounds and ages, including those with intellectual disabilities, may give back to their communities. In fact, every year, it dedicates several million dollars in funding to promote community service by people with all types of disabilities (<http://www.serviceAndInclusion.org>. or <http://www.nationalservice.gov>).

SUMMARY

The same creative approaches that prepare the general population for the world of work—career planning and exploration, internships, and volunteering—help transition students with intellectual disabilities into the workforce. Outcome-focused efforts are needed to build career-focused initiatives.

RECOMMENDATIONS

9. Promote national and community service for young people, fully integrating young adults with intellectual disabilities in the effort, as a means for transition to adult life.

Work with the Corporation for National and Community Service to expand service projects incorporating young people with intellectual disabilities from all backgrounds.

10. Expand investment in the Individuals with Disabilities Education Improvement Act of 2004 and the Rehabilitation Act's focus on transition plans for all youth with intellectual disabilities, including full federal funding of the Act.

- Develop and implement strategies to promote quality, career-focused outcomes in post-secondary education and employment in coordination with the Rehabilitation Services Administration, the Social Security Administration, and the Centers for Medicare and Medicaid Services.
- Ensure that competitive employment is included as a goal in transition plans for all youth with intellectual disabilities.
- Develop dissemination strategies to reinforce to the public sector the communication, information, and physical access standards of the Telecommunications Act of 1996 and the Rehabilitation Act.

V Family and Systemic Supports

For all of us, employment exists in the context of the rest of our lives. We incorporate our work within the complexities of day-to-day living, our families, our household budgets, transportation needs, priorities, and much more.

For people with intellectual disabilities, placing work within this context can be a complicated challenge. They often need services and supports for transportation or assistance. Government benefits and programs, while numerous, provide a dizzying array of possible benefits and are difficult to understand and access (Morris, 2008). These programs have not succeeded, overall, in promoting full employment for people with intellectual disabilities.

The following is only a partial list of programs that people with intellectual disabilities and their families must navigate to secure community employment and financial independence. Some of these supports go directly to families; others come in the form of payments to service providers.

- **Medicare and Medicaid**—These huge federal programs provide publicly financed health services to different populations of people with disabilities. Medicaid also covers the cost of a range of supports that enable people with disabilities to live in community settings instead of institutions and encourage employment with personal assistance, training, and outreach services.
- **Food stamps**—Another federal program, food stamps are usually offered as part of general benefit packages for families living below and near the federal poverty level.
- **Subsidized housing**—The U.S. Department of Housing and Urban Development administers programs that provide benefits to people who live in public housing developments and who qualify for “Section 8” housing vouchers. Local housing authorities implement these programs at the community level.
- **Supplemental Security Income**—SSI provided cash benefits to more than a million people with intellectual disabilities in 2007 (SSI Annual Statistical Report, 2007). The share of SSI beneficiaries who worked that year ranged from a low of 2.7% in Kentucky to a high of 18.5% in North Dakota. A significant work

incentive built into SSI is its pairing with eligibility for Medicaid benefits, which remain in force despite earned income.

- **Social Security Disability Insurance**—SSDI pays benefits to people who have worked and paid into the Social Security system but are unable to work at a substantial gainful activity level for a year or more because of a disability. In 2007, more than 338,000 people with intellectual disabilities received benefits under this program. SSDI also pays benefits to disabled adult children and disabled surviving spouses of eligible workers. In 2007, more than 367,000 disabled adult children and 9,000 disabled surviving spouses with intellectual disabilities received SSDI benefits (Annual Statistical Report on the Social Security Disability Insurance Program, 2007).
- **Vocational rehabilitation**—Recipients of SSI or SSDI are eligible to receive state-federal vocational rehabilitation (VR) services to help them enter or re-enter the workforce. VR services are usually time-limited and typically include training, higher education, counseling, assistive technology, transportation assistance (including assistance in using public transportation), as well as transition services for transition-age youth and supported employment.
- **Developmental disabilities agencies**—Public “DD” agencies, which are often part of state and county governments, authorize eligibility for publicly financed services and provide funding authorizations to private, non-profit agencies that assist individuals with disabilities in choosing appropriate employment, building job skills, and acquiring the training and support they need to maintain a job.

For people with intellectual disabilities and their advocates, the rules governing these programs can be impenetrable. They change over time and across jurisdictions. Information can be difficult to obtain, much less interpret. Rules designed to encourage people with intellectual disabilities to work are not only difficult to understand but are also difficult to administer. Recognition that change is needed is evident from the Social Security Administration’s Fiscal Year 2008-2013 Strategic Plan. An objective includes simplification of work incentive programs to “make it easier for disabled individuals to return to work” (<http://www.ssa.gov/strategicplan>).

Some programs require limits on assets and incomes that may keep even full-time workers living at or near the poverty level (Morris, 2008). SSI, for example, is subject to income ceilings—commonly called “break-even points”—that vary based on individual case circumstances. SSI also limits recipients to owning only \$2,000 in liquid assets. Many advocates for people with intellectual disabilities have urged the removal of income limits on earnings and accumulation of assets for people so they don’t present a barrier to employment.

Few comprehensive studies have addressed how public and private programs for people with intellectual disabilities can be aligned with employment goals and incentives. It is clear that these federal programs must be considered together rather than separately in seeking to promote employment. In particular, the inter-relationships of SSI, SSDI, Medicaid and Medicare must be recognized and addressed to align these programs with worthy employment outcomes.

***Lindsay** has an intellectual disability and is receiving Supplemental Security Income payments from Social Security (SSA). She lives with her parents and was in the Transition Program at the local high school. Lindsay assigned her Ticket (from SSA’s Ticket to Work Program) to an Employment Network called Career Connection in September 2004. She began working at Togo’s Eatery, successfully completed her probationary period and is working full-time. The Employment Network not only helped her prepare for and find her job, but it also helped her arrange transportation to and from work. It helped her understand her reporting responsibilities, SSA’s work incentives, and how work affects her SSI benefits. Lindsay is such an excellent employee that when the owner/manager is out of the office, Lindsay is the acting manager. Her employers are very satisfied with her abilities, attendance, and customer service skills. Although she is still receiving SSI, she has been able to reduce her dependence on public benefits.*

The program that has the greatest impact on the lives of people with intellectual disabilities is Medicaid. Since 1981, the Medicaid Home and Community Based Services (HCBS) Waiver has channeled resources to states to increase reliance on community-based, rather than institutional services for individuals with intellectual disabilities and their families. Today, Medicaid finances more than half of all family support services in the country, including “case management, homemaker assistance, home health aides, personal care, residential and day habilitation, transportation, supported employment, home modification, occupational, speech, physical, and behavioral therapy, and family support and respite care” (Braddock, 2008).

As noted earlier, most state spending on programs for people with intellectual and developmental disabilities supports non-employment and segregation rather than integration and productivity. A shift in emphasis to achieving employment outcomes in community settings would lead the way for other state and local agencies with vocational rehabilitation and developmental disabilities resources to focus on employment.

SUMMARY

People with intellectual disabilities and their families must navigate an intricate web of public and private support programs that provide essential services but can actually present barriers to community employment. Changes in the largest support program, Medicaid, and the realignment of the focus of all state and local day programs to community employment would have the greatest impact in achieving favorable employment outcomes.

RECOMMENDATIONS

11. Expand investment in the Rehabilitation Services

Administration related to funding supports for transition from school to adult life.

Issue U.S. Department of Education guidance encouraging the use of vocational rehabilitation funds to support students with intellectual disabilities in transition to employment and post-secondary education programs, including higher education, from as early as age 14.

12. Increase incentives to work and remove income limits governing benefit programs for people with intellectual disabilities, and promote these incentives.

- Create a federal interagency workgroup to develop a coordinated and comprehensive approach focused on incentives for economic empowerment.
- Work with the Social Security Administration to refine work incentive policies.
- Expand Medicaid “buy-in” provisions, which allow states to expand program benefits to workers with disabilities whose incomes would otherwise make them ineligible, thus protecting health care benefits.
- Provide tax incentives, to individuals and families, for employment support services such as personal assistance, transportation, and

assistive technology.

- Establish public-private partnerships to support people with intellectual disabilities during transition from school to adult life.

13. Refocus existing resources to promote integrated employment.

- Work with the federal Centers for Medicare and Medicaid Services related to Medicaid waivers to promote community outcomes rather than services in segregated settings.
- Develop and facilitate implementation of educational programs that are culturally sensitive and likely to increase positive outcomes in the lives of people with intellectual disabilities.

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