



PEOPLE WITH INTELLECTUAL DISABILITIES

Critical Supports that Promote Independence,

Full and Lifelong Community Inclusion

2011

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



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President's Committee for People with Intellectual Disabilities
Washington, D.C. 20447

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

Dear Mr. President:

As Chairman of the President's Committee for People with Intellectual Disabilities (PCPID), I am pleased to forward to you a copy of the Committee's annual report, *PEOPLE WITH INTELLECTUAL DISABILITIES: Critical Supports that Promote Independence, Full and Lifelong Community Inclusion*, in keeping with your Executive Order 13585. As requested in the Executive Order, the Report is being delivered to you through the Secretary of Health and Human Services.

The President's Committee for People with Intellectual Disabilities is very concerned about the potential impact of the *Budget Control Act* and related deficit-reduction activities on people with intellectual disabilities and their families. We feel a sense of urgency, and want to call to your attention the possible effects of reduction or elimination of government programs and services. This population is very aware of the potential harm, and the potential opportunity, that may come through budget and policy changes currently being debated. Persons with intellectual disabilities, and their families, have been and will continue to vote and be part of the democratic process that is both our right and our responsibility.

Integral to the mission of the Committee is the promotion of policies and initiatives that support independence and lifelong inclusion of people with intellectual disabilities in their respective communities. Current government investments provide considerable support in helping people with intellectual disabilities experience home and community living and full participation in all aspects of our society. The Committee's primary concern is that potential reduction or elimination of such programs and services will significantly impact the daily lives of this population of Americans by reducing their independence and challenging their ability to live, learn and work as contributing members of our communities.

With the current contexts of the deficit reduction debate, PCPID has identified critical federal programs and services, including public investments in education, employment, health care, income support, and long-term services and supports. This Report, Mr. President, presents current information from experts in the field, advocates, and self-advocates regarding the need for continuing government support in these critical areas and how the lives of people with intellectual disabilities will be affected should current programs, services, and benefits be significantly reduced or eliminated.

Mr. President, thank you for accepting and considering the contents of this Report. I trust that you will find the Report a worthy contribution to your Administration.

Sincerely,

James T. Brett
Chairman, PCPID

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Introduction

As a nation, we are enriched by the contributions of individuals with disabilities. In the almost 50 years since President Kennedy commissioned a panel to focus attention on our national responsibility to our fellow citizens, individuals with intellectual disabilities (ID) and their families have come out of the shadows.

People with ID are an integral part of the social fabric of our country. As a society, we have learned to recognize and support the capacity and gifts of people with ID. Many children with ID go to the local school with their siblings and neighbors. Young adults with ID are now beginning to pursue postsecondary education, far exceeding the low expectations and societal misperceptions that have limited options for people with disabilities and hinder our productivity as a nation. Individuals with ID are workers contributing to the economy, although they largely remain unemployed or underemployed. They fully participate in volunteerism and civic life, including voting.

In contrast to a long history of isolation and segregation, children with ID are now growing up living with their families within the community. This has been made possible by the support we, as a society, provide to our fellow citizens.

For families, having their children live quality lives at home has been made possible through important federal policies including the Individuals with Disabilities Education Act (IDEA), Medicaid Home and Community-Based Services, Supplemental Security Income (SSI), and enforcement and implementation activities stemming from the Supreme Court's Olmstead decision under the Americans with Disabilities Act, *Olmstead v. L.C.*, 527 U.S. 581 (1999). The combination of civil rights protections and supportive programs has allowed people with ID to live within our communities and not rely on costly segregated institutions.

People with ID and their families are citizens in every state and community of our country. Intellectual disabilities know no socioeconomic, ethnic or geographic boundaries and are not the province of any political, social or cultural group. People with ID and their families share the commonality that the availability and judicious use of support from social programs are critically important for survival and full engagement in community life. Ensuring that people with ID are included fully in our communities requires support from all sectors of our society. For our nation, providing supports to individuals with ID and their families makes sense: humanly and economically.

Employment

Background: Like all Americans, people with intellectual disabilities (ID) want jobs. Employment brings income, a higher quality of life, and dignity to all citizens and is an essential part of the American Dream.

Employment of individuals with ID can play an important role in balancing the federal budget. Individuals with ID employed in integrated, community-based jobs at competitive wages are much less reliant on government benefits, contribute to the public good through paying taxes and address a workforce need.

There is ample evidence that those with ID, given appropriate training and supports, can become loyal, productive and immensely valued members of a diverse work force. Just ask corporations — Marriott, Walgreens, and Bank of America — or the thousands of small business owners and government agencies across the country. They will attest to the fact that workers with disabilities are valued and contributing employees.

Yet the statistics remain dismal. In June 2010, the Bureau of Labor Statistics (BLS) reported that 70.5% of non-disabled Americans under the age of 65 had jobs. The figure for those with disabilities was 21.7% (U.S. Department of Labor, BLS, 2010). The employment rate for people with ID is even worse. The Arc, a leading advocate for individuals with ID, with national reach, recently surveyed its clients and found that 85% were not working (Scott, 2011).

Services/Needs: Federal programs are key to turning this statistic around. The Individuals with Disabilities Education Act (IDEA) provides federal dollars to support public education services for children with ID age 0-21, and the Elementary and Secondary Education Act requirements hold public schools accountable for the achievement of students with ID. For many individuals with ID, one critical part of their later years of public education may include

vocational training. Postsecondary programs for students with ID in institutions of higher education have seen remarkable growth in the last few years, spurred in part by the Higher Education Opportunity Act of 2008.

Federal investments include an \$11 million demonstration program administered by the Department of Education that currently funds 27 model projects across the nation (U.S. Department of Education, 2011). The Administration on Developmental Disabilities (ADD) has invested \$4.5 million in research, training and technical assistance, and information dissemination related to postsecondary options for students with ID. Many of these postsecondary efforts further improve the employment skills of people with ID, and all have positive employment outcomes for their students as a primary goal. With low-income individuals attending some of these programs now eligible for Pell Grants and other federal financial aid, many more individuals with ID will benefit from postsecondary opportunities.

State Vocational Rehabilitation (VR) agencies (which receive 78% of their funds from the Rehabilitation Services Administration at the Department of Education) are putting new emphasis on working with school districts on effective transition programs and often play a leading role once students age out of the public school system. VR agencies help job seekers with ID assess their interests and strengths, develop marketable skills and find employment. They provide job coaching and supportive services at the work site until the employee is established.

Workers who need additional training or assistance in job-specific skills to gain employment or remain employed can use services offered through Medicaid waivers, which provide employment supports delivered in community settings. While waiver waiting lists are extremely long in many states (a decade's wait is not unusual), Medicaid waiver support is a

mainstay for millions. One of the brightest spots on the horizon is a series of clarifications issued in September of 2011 by the Centers for Medicare and Medicaid Services (CMS), which both emphasize and facilitate the goal of integrated, community employment for waiver recipients.

Also cause for optimism is the focus on employment in a variety of other government agencies and programs. Executive Order 13548 directs executive departments and agencies to improve their efforts to employ persons with disabilities through increased recruitment, hiring, and retention. It demonstrates the President's strong commitment to making the federal government a welcoming place for people with disabilities where they can thrive and make the most of their talents and abilities.

Additionally, federally sponsored efforts have been launched in the past year, including 16 state projects supported by the Department of Labor to improve education, training and employment opportunities for youth and young adults with disabilities. The Administration on Developmental Disabilities within the Department of Health and Human Services (HHS), has announced over \$3 million in grants that will allow consortia of education, employment, and developmental disability agencies in six states to improve competitive employment outcomes for youth and young adults with intellectual and developmental disabilities.

Equally important, a few states – working across agency lines and using federal dollars as a critical part of their funding mix – have developed successful models that others can replicate. Many are now embracing “Employment First” policies that make integrated employment the priority goal across government-funded services. Multiple studies have conclusively shown that the dollars spent on supported employment services for workers with ID save money on public benefit programs like Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI).

**Employment Recommendation: DEFICIT REDUCTION EFFORTS AND
FEDERAL POLICY INITIATIVES MUST ADVANCE EMPLOYMENT
OPPORTUNITIES FOR ADULTS WITH INTELLECTUAL DISABILITIES TO
ENABLE MORE TO BECOME TAXPAYERS AND REDUCE DEPENDENCE ON
GOVERNMENT BENEFITS.**

As a nation, we have invested millions of dollars — through the public school system, Medicaid waivers, vocational rehabilitation services and other government programs — to provide individuals with ID the education and training they need to become active citizens and contributing wage earners in our communities. The Committee recognizes, with appreciation, the public policymakers, service providers, researchers, institutions of higher education and a wide range of employers and private sector partners who have identified the next steps needed to help individuals with ID to realize that dream. We also recognize that it will not happen without continued federal investment in services and programs authorized under the IDEA, without continued federal investment in VR services, and without a focus upon competitive, integrated employment at a living wage through federally-funded Medicaid waiver services. The return on these investments will be quantifiable in terms of increased tax revenues and reduced strain on programs like SSI and Medicaid. It will be priceless with respect to the enhanced quality of life for millions of individuals with ID, and to the spirit and humanity they will bring to their workplaces and communities.

Employment: A Real Life Experience

We, Brenda (44) and Matt (38) Petke, were married in 2001. I (Brenda) was born and raised in Maryland, attended public schools and completed my education. Matt graduated from a residential special education program.

Together, we live an independent life full of family and friends. We both work at Bank of America, and with two salaries and some help from Matt's family, we were able to buy a home. We manage our own money with some support, and drive together to work in Matt's car. We have two dogs, are involved with Canine Partners for Life, enjoy entertaining, and often invite our friends and coworkers over for dinner.

We are keenly aware of the serious economic situation, and Bank of America's recent announcement of layoffs. When asked what would happen if we were terminated, we respond, "We don't know, it's scary." Sadly, if this were to happen we would join the ranks of the 85% of people with intellectual disabilities who are not working in competitive, integrated employment. We would be forced back into the very dependent system from which we have worked so hard to escape.

Brenda and Matt Petke
Wilmington, Delaware

Income Support

Background: Income support programs, in particular the SSI program and the SSDI program, play a critical role in preserving the economic well-being of people with ID. In December 2010, 141,701 children under the age of 18 with intellectual disabilities received SSI payments, and another 935,783 adults with intellectual disabilities ages 18 to 65 received SSI payments (Social Security Administration, 2010). In 2010, SSDI program paid benefits to 745,213 people with intellectual disabilities. Thus, any changes to these programs that reduce the real value of benefit payments will hurt well over a million people with ID who rely on them.

Services/Needs: Unfortunately, the SSI payment received by many people with ID has not kept pace with increases in the cost of living for SSI beneficiaries. After two years with no cost-of-living increase, in 2012 the maximum monthly SSI benefit will increase 3.6 percent, to \$698 for an individual and \$1,048 for a married couple. The SSI program \$20 general income exclusion and \$65 earned income exclusion have not changed since the program was implemented in 1974. Some states have recently reduced the SSI state supplement for SSI recipients.

Changes to the program that do not keep pace with cost of living increases will reduce the already low income support that people with ID receive from the program, and the “marriage penalty” that couples experience further diminishes the value of the support.

In particular, PCPID is concerned about the difficult and long process to access benefits, including application processing delays and the two-year wait period for SSDI beneficiaries seeking eligibility for Medicare. Inadequate administrative support for the program will result in additional delays and frustrations for people trying to access benefits.

**Income Support Recommendation: DEFICIT REDUCTION EFFORTS AND
FEDERAL POLICY INITIATIVES MUST PRESERVE A SAFETY NET FOR PEOPLE
WITH INTELLECTUAL DISABILITIES, CONTINUING AT LEAST A SUBSISTENCE
LEVEL OF INCOME SUPPORT FOR OUR MOST VULNERABLE CITIZENS.**

We urge you to reject any changes to either the SSI or SSDI programs that reduce the real value of these benefits for the more than 1.3 million people with ID who rely on these important programs. Furthermore, we urge you to mandate that the government continue efforts to fix longstanding problems with the administration of the programs that have prevented these programs from effectively supporting our most vulnerable citizens. With a sense of urgency, the application process for disability benefits needs to be simplified, emphasizing the elimination of long processing times, excessive waiting periods, delay in benefits eligibility, and the marriage penalty.

Income Support: A Real Life Experience

My name is Joe Steffy and I am a 23-year-old small-business man with a goal of \$100,000 in sales by 2012. I also have autism and Down syndrome and am nonverbal. When I speak, I push buttons on an augmentative speech device to deliver the words. My audiences usually are parents who fervently hope their own special-needs children will be able to work, too.

My parents, Ray and Janet did not agree with the assessment of the school district in which they lived previously, which had said I would never be able to work or live independently. "I am one who can easily get ticked off," says Ray. "That ticked me off. We saw more in Joe than that. We set out to prove to the school that he had capabilities." They came across kettle corn while on a trip to Alaska and realized that all that popping, scooping, and serving suited Joe's love of work.

The path to my success was not an easy one; my father worked closely with Dave Hammis, an advocate for self-employment for people with disabilities in Middletown, Ohio, who trains business owners, government employees, and parents on how to make use of state and federal programs. My family wrote up a business plan and helped me secure \$25,000 in grants from programs like the Social Security Administration's Plan to Achieve Self-Support program (PASS).

In 2005, Poppin' Joe's Kettle Korn was born. Sales have grown from \$16,000 in 2005 to \$50,000 in 2008, both from selling at festivals and from delivering popcorn to local outlets. I have five part-time employees, and my parents help out with driving and other tasks. "Pop and everyone that works with him knows whatever Joe wants to do you let him do, because he's the boss," Ray says. "If he wants to pop, he'll shove Dad out of the way and pop."

If the business stays on track, it should be grossing more than \$100,000 in three years, and we are seeking a business partner who can work with me to manage the business. I am no longer on Social Security disability payments; instead, I pay state sales tax and state and federal income tax. I rent my own house and receive help by caregivers who are paid by a state program.

The payoff for that effort, as far as my family is concerned, has been priceless. My family sees me as a son who makes a local popcorn delivery, accept payment, fold it, and put it in his pocket. When I walk out, my dad says, you look 3 inches taller than when you walked in.

Joe Steffy
Overland Park, Kansas

Long-Term Services and Supports

Background: Federal policy and financial assistance for long-term supports and services, are critical for people with ID to be included in our society. For adults with ID, long-term services and supports (LTSS) provide a crucial lifeline that assists them to live in diverse neighborhoods, attend school, work and be engaged in all aspects of community life.

Today, the Medicaid program is the primary funding source for the vast majority of long-term services and supports.¹ Under the Medicaid program, states are required to provide institutional care to individuals with ID who are in need of that level of care. States are authorized, but not required, to provide home and community-based services as an alternative to institutional care. Over time, the trend has been for states to move away from more costly institutional forms of care in favor of home and community-based services, and several states have completely eliminated institutional care for people with intellectual and developmental disabilities. A broad range of home and community-based services are provided, including but not limited to: personal care assistance, respite services, employment supports, and variety of supported living opportunities. The specific services available vary considerably from state to state.

Since states are not required to offer home and community-based services to all eligible individuals, waiting lists for such services are extraordinarily long in many states. The Kaiser Foundation estimates that nearly a quarter million people with intellectual and developmental disabilities are waiting for home and community-based waivers.¹ In a nationwide online survey

¹ In 2008, the United States spent \$43.8 billion on Medicaid-funded supports for people with developmental disabilities. Braddock, D., Hemp, R., & Rizzolo, M. C. (2008). *The State of the States in Developmental Disabilities (Seventh edition)*. Washington, DC: American Association on Intellectual and Developmental Disabilities.

conducted by The Arc, in 2011, 32% of families reported that their son or daughter with intellectual and developmental disabilities was waiting for government funded services, with an average wait of 5.3 years, suggesting the number of individuals who are not served may be much larger.

Reportedly, most adults with ID either live at home with their parents or with other family members.² Home and community-based services are unavailable to them and affordable housing options are extremely limited. Unfortunately, too many adults with ID continue to live in state institutions, nursing homes, and similar congregate facilities.

Services/Needs: Home and community-based supports are one of the most important public services provided to help individuals with ID live as independently as possible. Parents of adult children with ID envision the time when their children are able to leave home, as most parents do. Correspondingly, these adult children with ID seek self-determined lives and meaningful adult relationships. Home and community-based services supported through Medicaid are critical in ensuring this opportunity is available for these individuals and their families.

Home and community-based supports are critical for solving a huge societal problem that looms on the horizon – what will happen to all of the adults with intellectual and developmental disabilities living at home when their aging parents are no longer able to provide for them? Estimates are that there are more than 2.9 million families caring for a family member with an

² See, e.g., Research and Training Center on Community Living, Institute on Community Integration, “Family Support Services in the United States: 2008” (2009). “In 2006, an estimated 4.7 million Americans had ID/DD (Larson et al., 2000), and approximately 60% of these individuals lived with family caregivers. An additional 15% of individuals with ID/DD lived with a spouse, and 13% lived in their own home. Twelve percent lived in “supervised residential settings” (Braddock et al., 2008; Fujiura, 1998); supervised residential settings include public and private institutions, nursing facilities, group homes, apartments, foster care placements, and supported living/personal assistance settings (Braddock et al., 2008). The “informal” system of residential care was five times greater than the formal out-of-home residential care system (536,476 individuals) (Braddock et al., 2008).

intellectual or developmental disability of which only 490,000 are currently receiving any services or supports.³ In 2009, there were an estimated 731,000 individuals with intellectual and developmental disabilities living with caregivers who were age 60 or older; an additional 1 million of these individuals were living with caregivers age 41-59.⁴ In The Arc's 2010 national FINDS survey, 62% of parent caregivers reported that they do not have a living arrangement plan for their son or daughter with intellectual and developmental disabilities when they get older.

Long-term Services and Supports Recommendation: DEFICIT REDUCTION EFFORTS AND FEDERAL POLICY INITIATIVES MUST MAKE HOME AND COMMUNITY BASED LONG-TERM SERVICES AND SUPPORTS WIDELY AVAILABLE TO AVOID UNNECESSARY, INAPPROPRIATE AND COSTLY INSTITUTIONAL CARE.

PCPID is concerned that the plans for deficit reduction may put at risk the progress that has been made in long-term services and supports for people with ID. Funding must be maintained for home and community based services and continued priority given to moving away from older, expensive forms of institutional care. If public investments in optional home and community services are reduced, the opportunity for people with ID to live in home and community settings of their choice will decrease, cutting off what may be the best option for an independent, fulfilling life.

Shrinking availability of public resources and supports means that family members of adults with ID, already under considerable strain, will be forced to shoulder additional financial,

³*The State of the States in Developmental Disabilities*. Washington, DC: American Association on Intellectual and Developmental Disabilities (Braddock et al., 2011).

⁴*The State of the States in Developmental Disabilities*. Washington, DC: American Association on Intellectual and Developmental Disabilities (Braddock et al., 2011).

physical and emotional responsibilities. Families without the strength or resources to care for these adults may be forced to turn to the only other option available: state institutions or nursing facilities, the most restrictive, most expensive, and often least desirable long-term care models available.

Reducing and eliminating home and community-based services and supports will also have significant economic consequences for parents, other family members, and society as a whole. In The Arc's FINDS survey, one in five families reported that someone had to quit their job to stay home and care for their family member with intellectual and developmental disabilities; two-thirds reported having to put their careers on hold. Any further decline in services and supports for these families will certainly lead to additional departures from the workforce and exacerbate already challenging family financial circumstances.

Preserving and expanding home and community-based support services through Medicaid, while continuing to move away from institutional forms of care, are viable options that will ultimately lead to lowering taxpayer expenses while improving the quality of life for people with ID and enriching our nation.

Long-Term Services and Supports: A Real Life Experience

My wife and I have three daughters, including identical twins who both have severe intellectual disabilities and autism. When my twins were 8 years old, the stress of raising two children who had constant meltdowns, bit and scratched everyone around them, and were not toilet trained, had reached the boiling point. My wife and I fought daily and our oldest daughter was witnessing the loss of her family and childhood.

As my twins continued to sit for years on waiting lists for community-based Medicaid waiver services, and no other options at hand, I contacted a local advocacy group in search of a place who could take our twins. As we clearly were in crisis mode, we qualified for state funds available through our school system to provide respite support. We were approved for that support and our first attendant joined us three weeks later. When she arrived, the stress on my family was reduced in an unimaginable way and our children were able to continue being raised by those who love them most.

These funds provided support until our twins reached the top of one of the Medicaid waiver waiting lists, which now enables their respite care. If that support is removed, I have no doubt my family will fracture and we will be forced to consider state placement options, which will not only increase the cost of my children's care, but literally break up our family. Like all parents, we look forward to the day all of our children are living under their own roofs. Until then, our children deserve as traditional a childhood as possible, and the cornerstone of that childhood is grounded in our family staying together. Medicaid waivers are critical in making that happen.

Clay Boatright
Plano, Texas

Education

Background: Education begins at birth. Part C of the Individuals with Disabilities Education Act of 2004 (P.L. 108-446) recognizes the need to enhance the development of infants and toddlers with disabilities, minimizing their potential for developmental delay, and recognizing the significant brain development that occurs during a child's first three years of life.

Early intervention is a crucial step in the development of young children. The onset of the majority of ID occurs during the first years of life, but this disability is usually not fully diagnosed until the children reach school age. While approximately 350,000 young children receive services under Part C of IDEA each year, the exact number of infant and toddlers with ID is not known (Markowitz et al., 2006). Data from a study of pre-school children age 3 to 5 served under IDEA suggest that 19% have a developmental delay (Markowitz et al., 2006). In subsequent years of education, as diagnoses of ID are cast with more precision, about 8 to 9% of schoolchildren are classified as having ID (Child Trends Data Bank, 2006).

Intervening early to prepare infants, toddlers and preschoolers with ID to enter kindergarten, ready to learn and to be successful, is the foundation that allows them to participate in the general education curriculum. Students with ID are, first and foremost, general education students who deserve high expectations, presumptions of competence, and access to the grade level content with appropriate supports and accommodations. All teachers, including special education teachers, must be prepared to meet the needs of diverse learners, including students with ID. Assessments must accurately and appropriately measure the performance of students with ID in order to truly achieve inclusion and improve academic outcomes for all students.

Pre-school and school aged children with ID receive special education and related services under Part B of IDEA. Statistics provided by the IDEA data center show that, in 2009,

12,403 children with ID age 3 to 5 in the United States and outlying areas were served under IDEA. This number represented only 1.75% of all children with disabilities in this age cohort. The count grew to 151,594 (or 5.65% of all students with disabilities) in the 6 to 11 years of age cohort, and 251,111 (or 8.8% of all students with disabilities) in the 12 to 17 years of age group. The 18 to 21 age cohort included 73,426 students with ID (21.2% of all students with disabilities). 64,476 (or 9.3 percent) of students with ID in the 14 to 21 year age cohort left school during that year. Of these, 16,626 (25.8%) graduated with a regular high school diploma, 15,324 (23.8%) received a certificate, and 8,511 (13.2%) dropped out. A small number (2,024 or 3.1%) transferred to regular education. The remainder reached maximum age of service eligibility, continued school elsewhere, or died.

In recent years, students identified with ID have been integrated increasingly into regular school settings and have participated in the general education curriculum in greater numbers. Facts from the National Longitudinal Transition Study 2 (Newman et al., 2009) show that 94% of students identified with ID attended regular schools serving a wide variety of students, and four percent attended special schools serving only students with disabilities. The other two percent attended charter, magnet, alternative, hospital, or home schools. Students with ID took at least one class in general education in 69% of cases, with foreign language learning topping the list of subject areas (44%), followed by science (30%), social studies (29%), language arts (16%), and math (15%). Students with ID who took technical and vocational courses did so in a general education setting in 44% of cases (Newman et al., 2009).

Services/Needs: Much progress has been achieved for students with disabilities since Congress enacted the Education for All Handicapped Children Act, Public Law 94-142, in 1975. This landmark law, together with subsequent amendments as currently reflected in the

Individuals with Disabilities Education Improvement Act of 2004; Public Law 108-446, supports states and localities in protecting the rights of, meeting the individual needs of, and improving results for infants, toddlers, children, and youth with disabilities and their families. Before IDEA, too many children with disabilities were denied access to education and opportunities to learn. Postsecondary education opportunities for students with ID became available in the early 1970s. As many as 40 college-based programs provided job training, instruction in independent living, and community-based education opportunities (Bilovsky and Matson, 1974). Today, over 250 colleges and universities provide some type of postsecondary education for about 6,000 students with ID.

Responding to demands for educational opportunities and improved career preparation for students with ID after high school, Congress provided funding to the U.S. Department of Education to support transition and postsecondary programs for students with ID in 2010, as authorized in the Higher Education Opportunity Act of 2008 (P. L. 110-315). These programs demonstrate the academic and social inclusion of students with ID in academic courses, extracurricular activities, and other aspects of each institution's regular higher education programs. They give students with ID (currently numbering somewhere between 650 and 700 in the 27 supported programs) the opportunity to attend college.

Regarding students with ID from diverse backgrounds, minority children continue to be served in special education in disproportionate rates compared to the percentage of minority students in the general school population. African-American children are identified as having intellectual disability and emotional disturbance at rates greater than their White counterparts. The latest statistics released by the U.S. Department of Education (2010) show that of a total of 65.8 million children and youth between age 6 and 21 in 2005, only 9.92 million (15%) were

African-American. African-American children and youth, however, constituted 33% of students with ID served under IDEA. On the other hand, the statistics show that 11.84 million students in the general school population (18%) were Hispanic, whereas Hispanic children and youth with ID accounted for 15% nationwide. Further exploration of factors that may lead to over- and under- representation of minority students in special education is warranted.

Education Recommendation: DEFICIT REDUCTION EFFORTS AND FEDERAL POLICY INITIATIVES MUST PRESERVE AND ADVANCE QUALITY, INCLUSIVE EDUCATION OPPORTUNITIES FOR STUDENTS WITH INTELLECTUAL DISABILITIES.

PCPID is concerned that potential budget cuts at the federal level will put infants, toddlers, children, and youth with ID at risk with reductions in currently available supports and lack of enforcement of federal requirements. In particular, the Committee would like to see stronger IDEA enforcement and accountability, especially related to civil rights, inclusive education in the least restrictive environment, and access to free appropriate public education. PCPID also has concerns about policies such as waivers to maintenance of efforts requirements, and the impact such reductions will have. Education funding for early learning and transition services, teacher preparation for both general education and special education teachers, postsecondary programs and access to Pell Grants are all important to students with ID.

The Committee is concerned that budget cuts and weakened accountability standards will result in lower expectations for students that will reverse 35 years of progress in full access to education opportunities. Other risks include increased segregation resulting in students with ID receiving a substandard education; reduced early intervention services resulting in increased severity of disability; lack of effective transition services and postsecondary education resulting

in decreased employability and increased reliance on SSI and dependence upon parents and families; and lack of teacher preparation and training resulting in ill-prepared educators.

If budget cuts result in diminished educational programs and services needed by students with ID, those students will be less able to develop into contributing members of their communities and more likely to become dependent on life-long government supports. Our nation's foundational values — and our hope for a more stable economic future — face serious erosion if we lose the progress made over the last 35 years.

Education: A Real Life Experience

My name is Oliver Dynes and I am 21 years old. I participate in the Career and Life Studies Certificate Program (CLSC) at the University of Delaware, Center for Disabilities Studies, one of the Transition and Postsecondary Programs for Students with Intellectual Disabilities funded by the Department of Education through the Higher Education Act.

I ride my bike to and from my group home to the University, where I attend classes five days per week. My classes include Introduction to Careers, History, and Goal Setting. I am hopeful that once I have completed my studies I will be able to find full-time employment.

Although this program is “up and running,” the Center for Disabilities Studies is concerned for the future because of pending budget cuts. In addition to my small salary, I receive SSI and am on the Medicaid waiver. Without this support, I would be unable to continue on my road to independence!

Oliver Dynes
Newark, Delaware

Health Care

Background: The ability to access affordable health care that includes all of the services and supports people with ID need to be fully included and participate in the community is of the utmost importance. People with ID have made significant progress toward being fully integrated into the community in recent years, with an increased focus on the provision of services in the setting of an individual's choice. As the health care landscape will shift significantly in the near future with the implementation of the Affordable Care Act (ACA), and the possible effects of changes made in response to the fiscal situation faced by both the federal and state governments, it is vital that the progress made is protected and that integration of people with ID in the community continues to be fully supported by available health care services and supports.

Services/Needs: People with ID need to have access to all necessary health care and services, including preventive care, to lead healthy, independent lives. Health care available to a person with ID should provide the full spectrum of necessary health services and should not be solely dependent on what an individual state provides by their definition of services available. This is especially important given the current fiscal environment, and we must ensure that state and federal budget cuts do not negatively impact Medicaid-funded health care services available to people with ID.

The Affordable Care Act (ACA) will improve health care access for people with ID by prohibiting the denial of coverage for pre-existing conditions, eliminating annual and lifetime caps on coverage, and providing the uninsured with options to obtain coverage that would otherwise not be available.

Health Care Recommendation: DEFICIT REDUCTION EFFORTS AND FEDERAL POLICY INITIATIVES MUST GUARANTEE ACCESS TO QUALITY, ACCESSIBLE HEALTH CARE FOR PEOPLE WITH INTELLECTUAL DISABILITIES, REDUCING THE HEALTH CARE COSTS THAT ARE INCIDENT TO PREVENTABLE SECONDARY MEDICAL CONDITIONS.

PCPID is concerned that plans for deficit reduction not put at risk the progress that has been made in health care for people with ID. Funding must be maintained for primary medical and dental care, as well as mental health services, durable medical equipment and other essential health care services. In addition, the Medicaid program must not be converted to block grants, which would most certainly have the effect of reducing available services and increasing health care disparities and out-of-pocket costs. As access to health care for all Americans expands with implementation of the ACA, it is vital to ensure that access for people with ID is not negatively impacted. Health care for people with ID must be affordable, accessible, and include all required care and services.

There are a number of opportunities under the ACA for better managing and reducing the costs of health care for people with ID, and a number of provisions under the ACA that improve opportunities for access to quality health care for people with ID: the elimination of pre-existing conditions; the opportunity for youth to stay under their parents' insurance; and the lifting of annual and lifetime caps. ACA also affects not only acute care health care, but also long-term supports that are essential to health and well-being. One place where a meaningful impact can be made is in the primary health and dental care areas that are not traditionally tailored to meet the needs of children and adults with ID. We recommend actively supporting collaboration with medical schools, universities and medical professional organizations to increase awareness

around treating people with intellectual disabilities within the entire medical community. Additionally, incentives for doctors must be developed, such as eliminating medical school loans if at least 50% of the patients they serve are people with ID. Incentives must also be provided for health care professionals to locate to rural and underserved areas. Within the ACA we recommend that the definition of essential benefits for Qualified Health Plans offered through the Health Insurance exchanges includes the provision of adequate coverage for durable medical equipment, therapeutic services and other services needed by people with ID. Increasing the supply of providers that are willing and able to care for people with ID will reduce their utilization and reliance on more expensive forms of care, such as emergency rooms.

Tight controls must be put in place for managed care systems, particularly as it relates to non-medical services. Managed care delivery systems should expand – not diminish – opportunities for people with ID and their families to select services and, to the degree they choose, to self-direct supports that will improve their quality of life. The needs of people with ID should drive the benefit package available to them, not the cost of the care and services.

Managed care delivery should encourage innovation in supporting people with ID and strategies that promote designing and implementing their own supports. For example, they should have access to technology and assisted devices to improve health care (i.e., tele-health, medication administration, remote monitoring, iPads and smart homes). Innovation in health care must include creative partnerships between all stakeholders and service systems, better use of natural and community supports, converting institutional services to community-based services, and examining opportunities to accomplish essential systems functioning more economically. “Natural supports,” however, must not be code words for denying essential out-of-home services and supports. The federal government must exercise effective oversight of state plans to ensure

that individuals with ID receive services in both scope and quality intended by the ACA and Medicaid.

Under any health care system, delivery must improve coordination with specialized services (acute/medical services) and not risk the quality of services for people with ID.

Although improved coordination between long-term supports and acute health care is necessary, resource allocation and care management must be identified and separated to ensure one support area does not compromise the intent and efficacy of the other.

Assisting people with ID to lead full, healthy and productive lives as active and valued citizens of their communities must continue to be the aim. This is best accomplished by providing essential health care and long-term services that are affordable and accessible, holistic, flexible, high-quality, personalized, culturally sensitive, simple to understand, and that honor individual choice. Falling short in providing these necessary services will mean increased dependence on expensive emergency, institutional and hospital services, as well as increased poverty for individuals with disabilities and their families.

Health Care: A Real Life Experience

We (Jody and Ryan Farris) are parents of a 10-year-old son, Nolan, who is partially blind, non-verbal, and has autism. Within three months of Nolan's birth, our family exhausted our private insurance and savings caring for our son. The waiting list for Medicaid was very long in Texas, and our family moved to Colorado after three months so Nolan could receive Medicaid benefits immediately. After spending the first year of his life in hospitals, Nolan was able to go home where he learned to sit, stand, walk, play and become more independent, thanks to Medicaid, Early Childhood Intervention, and home health care services.

Presently, through a home-based therapy program called Community Living Assistance and Support Services, Nolan is able to live with and be cared for by us. We fear that proposed cuts to such programs would make it impossible for Nolan to live at home, limiting his future and requiring additional costs such as paid care to look after him. Children need to be at home, need to be with their families. We cannot imagine telling Nolan's sister that he has to live in an institution because we cannot afford him. Cuts to such programs also could ultimately cost the taxpayers more money.

The Farris Family
Missouri City, Texas

References

- American Association on Intellectual and Developmental Disabilities (2010). Intellectual disability: Definition, classification, and systems of supports. Retrieved October 19, 2011, from http://www.aaid.org/content_100.cfm?navID=21
- Bilovsky, D. & Matson, J. (1974). The mentally retarded: A new challenge. *Community and Junior College Journal* 44(6), 16–18.
- Child Trends Data Bank (2006). Learning disabilities. Retrieved October 28, 2011, from http://www.childtrendsdatbank.org/pdf/65_PDF.pdf
- Markowitz, J., Carlson, E., Frey, W., Riley, J., Shimshak, A., Heinzen, H., Strohl, J., Lee, H., & Klein, S. (2006). Preschoolers' characteristics, services, and results: Wave 1 overview report from the pre-elementary education longitudinal study (*PEELS*). Retrieved October 28, 2011, from www.peels.org
- Newman, L., Wagner, M., Cameto, R., & Knokey, A. (2009). *The post-high school outcomes of youth with disabilities up to 4 years after high school. A report from the National Longitudinal Transition Study-2 (NLTS2)* Menlo Park, CA: SRI International.
- Scott, M. (2011). People with intellectual disabilities struggle with budget cuts, recession. Retrieved October 19, 2011, from <http://www.newsworks.org/index.php/health-science/item/21586-people-with-intellectual-disabilities-struggle-with-budget-cuts-and-recession>
- Social Security Administration (2010). SSI Annual Statistical Report. Retrieved October 12, 2011, from http://www.ssa.gov/policy/docs/statcomps/ssi_asr/2010/ssi_asr10.pdf

U.S. Department of Education, Office of Special Education and Rehabilitative Services, Office of Special Education Programs (2010). *29th Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act, 2007*, vol. 2, Washington, D.C.

U.S. Department of Education (2011). U.S. Department of Education awards nearly \$13 million for transition to teaching grants. Retrieved October 19, 2011, from <http://www.ed.gov/news/press-releases/us-department-education-awards-nearly-13-million-transition-teaching-grants>

U.S. Department of Labor, Bureau of Labor Statistics (2010). Labor force statistics from the current population survey. Retrieved October 9, 2011, from <http://www.bls.gov/cps/cpsdisability.htm>.

U.S. Department of Labor (2011). US Labor Department awards more than \$21 million in disability employment initiative funding to 7 states. Retrieved October 19, 2011, from <http://www.dol.gov/opa/media/press/eta/eta20111421.htm>

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