STATEMENT OF

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Chairman Harkin, Ranking Member Enzi and distinguished Members of the Committee, thank you for the opportunity to testify today. I am honored to be here representing the Administration on Developmental Disabilities (ADD) within the Administration for Children and Families (ACF) at the U.S. Department of Health and Human Services (HHS), to share some successful strategies to achieve integrated employment of people with intellectual and developmental disabilities.

The purpose of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) is “to assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life, through culturally competent programs…” (42 USC 15001). The Administration on Developmental Disabilities works with our partners in every state to achieve the goals embodied in the Act. The ADD network consists of three programs that operate in each state and territory -- State Developmental Disabilities Councils (DD Councils), University Centers for Excellence in Developmental Disabilities (UCEDD), and Protection and Advocacy Systems (P&As). ADD also implements the Projects of National Significance (PNS) which are designed to support the ADD network through data and research projects as well as fund innovative approaches to improving outcomes for those with developmental disabilities. Approximately two-thirds of the ADD network entities report active engagement related to improving employment outcomes for people with developmental disabilities, through a broad range of activities including direct support for individuals with disabilities seeking employment, development of state and local policies and practices, protection of employment rights, data collection and analysis, and training initiatives.

At the Department of Health and Human Services, Secretary Sebelius is fully committed to finding solutions that address barriers to community living for individuals with disabilities that give people more control over their lives and the supports they need. Employment is a critical component of community living for most adults, including people with intellectual and developmental disabilities. Work is not only the
means to economic self-sufficiency, it also is an important way for individuals to contribute to their communities, build a network of social relationships, and create opportunities for lifelong learning.

To illustrate, I would like to tell you about a remarkable young man, Patrick, from Wisconsin. Like many young people, Patrick got his first job at 16. Patrick’s first job came the same way most of us get a job: a great work ethic, dedication, a terrific attitude, and a social network derived from community involvement.

Patrick met his boss, Todd, at a retreat where Todd had the opportunity to see first-hand Patrick’s work ethic, attention to detail, and generous spirit. At the end of the retreat, Todd told Patrick’s dad, Brian, that he would like Patrick to apply for a job at his packaging business in Menomonee Falls, Wisconsin.

As a high school sophomore, Patrick started working 3-hour shifts, three days a week after school. His starting pay was $8.50 in 2005. Five years later, Patrick is considered the star of his unit. He assembles boxes, and can work about twice as fast as the average box assembler – he holds the assembly record. This has increased the overall productivity of Todd’s organization. Patrick is able to work in different parts of the organization, filling in when another area is short-staffed – doing marketing and label packaging, for example. He gets regular raises and shares in all the company perks.

This is a success story of a typical young man, starting his career and through his hard work and dedication achieving great success. Why is this story significant? Patrick is a young adult with Down syndrome who is working in integrated employment, earning a competitive wage and benefits. Only a small minority of young adults with intellectual and developmental disabilities are employed in such settings. In one current study of 338 recent high school graduates with intellectual and developmental disabilities, only 14.2 percent were employed in individual positions paying at least minimum wage.¹

Patrick’s success can be attributed to several factors, as described by the Wisconsin Medicaid Infrastructure Grant project at the University of Wisconsin’s Waisman Center:

- **High expectations and supportive family.** Patrick always has been treated the same as his siblings and his peers, with high expectations at home, in school and at work. Additionally, Patrick’s family received support to participate in leadership development through Wisconsin’s Waisman Center (a UCEDD) and the Wisconsin DD Council, which helped his family understand the importance of self-determination.

- **Hard work and preparation.** Patrick knows he has to work to achieve. He has been active in sports, volunteers on a regular basis, and has a second degree Black Belt in Tae Kwan Do. He has taken on additional responsibilities at work over time, and has been rewarded.

- **Person-centered thinking and self-determination.** Throughout Patrick's school-to-work transition process, Patrick and his team made decisions based upon his desires, strengths, and choices. Patrick and his family used person-centered planning to ensure the availability of natural and paid supports necessary for a quality life for Patrick.

- **Community involvement.** Patrick has been involved in sports, the community, and his church, which helped him develop the social capital that led to the job and provided ongoing natural supports.

- **Welcoming employer.** The company worked with Patrick to get his Occupational Safety and Health required training, accommodating Patrick with experiential learning rather than handing him a manual. Patrick has co-workers he can turn to for questions and support.

- **Flexible supports.** The school system and vocational rehabilitation (VR) system offered flexibility in supporting Patrick to pursue his goals, and Patrick depends upon Medicaid for healthcare and occasional personal support. For example, the

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school partnered with the state VR agency to provide a job coach for the first few weeks of Patrick’s job, and the school offered a flexible schedule to allow Patrick to balance work and continued learning.

- **Starting early.** Patrick started working during his sophomore year. When he finished the high school curriculum at the end of his senior year, he left the high school environment, increasing his time at work while continuing reading and math instruction through a tutor. Patrick focused on living and working in the community starting at age 18; he did not wait until he aged out of school-based services. This is consistent with data that indicates that individuals with intellectual and developmental disabilities (ID/DD) who participate in work-based experiences during high school are more likely to find success in competitive, integrated employment.

While Patrick has found great success in his job, unfortunately many Americans with disabilities, especially people with ID/DD, are struggling to access employment opportunities. According to the January 2011 Current Population Survey (CPS), the proportion of the population of people with disabilities who are employed is estimated to be 17 percent, compared to 63 percent for people without disabilities. And, for individuals with intellectual and developmental disabilities, the likelihood of participating in integrated employment is even lower, with state ID/DD agencies reporting that only 22 percent of the number of individuals served by these agencies participating in integrated employment.

Among the strongest predictors of post-school employment success for young adults with disabilities is whether or not they held one or more paid jobs during high school. The importance of community-based vocational evaluation, job training, and

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paid employment opportunities while still in high school have been well documented in achieving positive post-school outcomes.\(^6\) Getting that first job can make a significant difference for students with intellectual and developmental disabilities, just as it did for Patrick.

**The Role of Education**

As is true for the general population, education is a key determinant in employment success for students with intellectual and developmental disabilities. Currently there are approximately one million American students with disabilities age 3-21 eligible for services under the Individuals with Disabilities Education Act (IDEA) categories of intellectual disability, multiple disabilities, autism, traumatic brain injury, and developmental delay.\(^7\) Only 34 percent of students with intellectual disabilities, 40 percent of students with multiple disabilities, and 56 percent of students with autism graduated from high school with a regular diploma during the 2007-2008 school year.\(^8\) Among all students, those with the most significant cognitive disabilities are the least likely to graduate with a regular high school diploma.\(^9\) And, even with a diploma, youth with intellectual disabilities demonstrate the lowest rate of paid employment among students with disabilities (29.8 percent), one to four years after exiting high school.\(^10\)

As states define, and re-define college and career-ready standards and develop supporting initiatives to help students achieve these standards, questions have arisen

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\(^7\) U.S. Department of Education. (2010). *Individuals with Disabilities Education Act Data – Data Accountability Center*. Number of children and students served under IDEA, Part B, in the U.S. and outlying areas by age group, year, and disability category, 2008. Table 1-11.

\(^8\) U.S. Department of Education. (2010). *Individuals with Disabilities Education Act Data – Data Accountability Center*. Exiting Children and students served under IDEA, Part B, in the U.S. and outlying areas by age group, year and disability category, 2008. Table 4-2.


about the applicability of such standards for students with intellectual disabilities, especially students with significant cognitive disabilities. Current data from states indicate that many of these students are leaving high school unable to read beyond sight words or do math beyond basic functions using a calculator. Low expectations continue to be one of the biggest barriers to success for these students. Yet maintaining high expectations for these students is critical to their success in life and in work; research has also shown that participation in standards-based assessments has made a tremendous positive difference in achievement for students with significant cognitive disabilities.

Despite these performance statistics and the cultural challenges of low expectations, students with intellectual disabilities can -- and do -- go on to succeed in post-secondary education and in employment. There are approximately 6,000 students with intellectual disabilities currently attending college, an experience which can make a tremendous difference in gaining employment. One recent study of vocational rehabilitation outcomes showed that youth with intellectual disabilities who participated in postsecondary education were 26 percent more likely than students with no postsecondary education experience to leave vocational rehabilitation services with a paid job and earn a 73 percent higher weekly income.

In order to provide more students the opportunity to attend quality college programs that support students with intellectual disabilities to participate in comprehensive, inclusive educational experiences integrated into institutions of higher education across the country, the Administration on Developmental Disabilities is

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investing $4 million over five years in the Consortium to Enhance Postsecondary Education for Individuals with Developmental Disabilities project. The Consortium is providing training and technical assistance to institutions of higher education, conducting research, and disseminating information on promising practices that support individuals with intellectual disabilities to access postsecondary education, resulting in improved long-term independent living and employment outcomes. The primary activities of the project include:

- Research and planning to develop and validate promising practices in postsecondary programs for students with intellectual disabilities including development of standards, quality indicators, and performance benchmarks.
- Development and testing of a national training program for colleges and universities that supports replication of promising practices and addresses gaps in information for institutions of higher education that are developing or expanding programs for students with intellectual disabilities. This includes the “Think College” website and online, self-paced coursework for higher education professionals on effective practices for this population.
- Assisting institutions of higher education to implement quality programs and establish partnerships that will help them transition to sustainable models beyond start-up funding periods, as well partnering with national organizations for large-scale dissemination of training programs.

During the past eight years, the number of college programs available for students with intellectual disabilities has grown from four to over two hundred fifty, spread over 36 states and two Canadian provinces. The Consortium has been a vital resource to these institutions of higher education, providing training and technical assistance to programs at all stages, researching and disseminating information on promising practices, and supporting the establishment of many of these new programs.

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Integrated Employment Supports and Services

Recently ADD held a series of listening sessions and stakeholder meetings across the country, asking the community to provide input about priorities and concerns. Approximately 650 individuals participated in-person in these meetings, including people with disabilities, family members, professionals and support staff as well as representatives from multiple federal agencies. Among the major issues identified by the community, access to integrated employment for people with intellectual and developmental disabilities was repeatedly cited as a top concern and was recommended as a critical priority for ADD and the ADD network to address. In particular, stakeholders identified the establishment of “Employment First” policy and strategies across various programs as one of five top goals that should be pursued.

Much of the ADD network already is working hard to improve integrated community-based employment opportunities at competitive wages for people with intellectual and developmental disabilities, with 39 P&As, 39 DD Councils and 36 UCEDDs reporting active engagement in employment activities, such as:

- In eleven states, DD Councils and/or UCEDDs (CA, HI, IA, IN, MD, NM, NC, NV, OR, PA, VT) are actively collaborating with the ID/DD state agency to develop and improve job access and retention. For example, in Iowa, the UCEDD assisted the Department of Human Services to update its Olmstead Plan that includes competitive employment as a "Strategic Priority." The action steps include working in collaboration with the national State Employment Leadership Network (SELN) and state agency partners (including the Iowa DD Council, Department of Education, Iowa Division of Vocational Rehabilitation Services (DVR), Workforce Development, Department for the Blind, Department of Human Rights) to develop and implement a statewide competitive employment plan that makes employment in the general workforce the first priority and expected and preferred outcome in the provision of publicly funded services. In Oregon, the DD Council convened a workgroup that developed the Employment First Policy which was then adopted by the state DD agency and is being implemented collaboratively with VR.
• Through a Medicaid Infrastructure grant provided by the Centers for Medicare and Medicaid Services, the Wyoming Employment Systems Development Project at the UCEDD brought together the various state agencies, disability groups and business organizations to determine the most effective means of permitting people with disabilities to retain their health care benefits after obtaining employment, working to expand personal assistance services outside the home for Medicaid recipients seeking employment, and integrating the various service systems into a single, one-stop source of delivery with a community focus.

• Project SEARCH is a nationally recognized education, training and internship program leading to integrated competitive employment for students with significant disabilities. Currently seven DD Councils (AZ, CO, FL, GA, NY, OH, OK) and three UCEDDs (AZ, IN, NY) are supporting Project SEARCH. In addition, ADD and ACF are hosting DC-area Project SEARCH interns in our offices this school year.

• The Alaska DD Council implemented the StartUp Alaska Initiative to increase the self-employment of Alaskans with disabilities. As a result, 71 individuals were served and 33 launched their own businesses. Even more importantly, several entities, including the Division of Vocational Rehabilitation, the Employment Security Division, the Alaska Mental Health Trust Authority, the Center for Human Development and the Center for Economic Development at the University of Alaska Anchorage, and the University Small Business Development Centers are implementing policy to sustain best practices identified through the grant.

• Vanderbilt University’s “Project Opportunity” provides educational, developmental and employment opportunities within Vanderbilt University to students with disabilities. Twenty-one of twenty-eight students have achieved competitive employment at the University upon completion. The Project also collaborated with The Arc of Davidson County, the Walmart Foundation and Metro Nashville Public Schools to use the Project Opportunity model to develop a classroom housed within the municipal government which then
became a model for the city of Nashville being implemented by Mayor Karl Dean.

- UCEDDs and/or DD Councils in twelve states (AL, CA, GA, IA, KS, MD, MO, NE, NV, OR, SC, UT) are working with state ID/DD agencies to establish “employment first” as a guiding principle in policy and systems change. Employment first is an approach that is underway in many states that focuses upon integrated, community-based employment as the first option and priority goal for individuals with intellectual and other developmental disabilities. States that have adopted this approach ensure that vocational rehabilitation, home and community-based service providers and educational service systems work together in developing strategies across programs so that individuals with intellectual and developmental disabilities are supported to access integrated, community-based employment opportunities.

Approaches to supporting access to integrated employment for people with intellectual and developmental disabilities vary tremendously across states. According to The National Report on Employment Services and Outcomes 2009 published by the Institute for Community Inclusion at University of Massachusetts Boston, the most important factors that influence integrated employment include:17

- **Approach of the state agencies directing Medicaid services for people with ID/DD:** Medicaid is both a primary source for health care for individuals with ID/DD and the largest federal source of funding for home and community-based services.18 State ID/DD agencies are playing a critical role in determining the direction of the state and federal Medicaid investment. In states that have started to address the need for competitive, integrated employment opportunities for people with intellectual and developmental disabilities, successful strategies include flexibility in funding, data collection focused upon integrated employment, rewards and incentives, and innovative practices and training. For example, in Oklahoma, an innovative outcome-based funding approach pays for

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18 Ibid, p. 11
services based upon the number of hours an individual works, not the number of service hours provided. In several localities in Michigan and other states, agencies have established rate structures that incent integrated employment outcomes.

- **Approach of the Community Rehabilitation Providers (CRPs):** As the primary source of day and employment services for people with intellectual and developmental disabilities, CRPs play a critical role in providing work opportunities. Currently, only twenty-six percent of individuals served by CRPs are working in integrated employment.

- **Collaboration with State Vocational Rehabilitation (VR) agencies:** Collaborative initiatives between VR and ID/DD agencies are an important element in supporting stronger employment outcomes.

- **Community-based non-work (CBNW) activities:** Participation in community-based non-work activities supported by home and community-based waivers and state funds – defined as activities that take place in the community and do not involve paid employment – has rapidly grown over the past 15 years, as reported by state ID/DD agencies.\(^{19}\) Thirty-eight state ID/DD agencies that reported CBNW services indicated that that 36.2 percent of those served participated in CBNW activities in fiscal year 2008, up from 18.7 percent in fiscal year 1999.

- **Direct Support Personnel (DSPs):** Competent support staff often play a key role in the success of people with intellectual and developmental disabilities on the job.

- **Individual and family factors:** Research has shown that many individuals with disabilities and their families want to consider community options, but have concerns about long-term placement and stability, safety, and the social environment.\(^{20}\)

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For people with intellectual and developmental disabilities, self-determination is another important factor in employment outcomes. Individuals with ID/DD who have the degree of control they desire over their lives consistent with their capacities, strengths and needs are more likely to express satisfaction with their individual employment outcomes. Research suggests that beyond the opportunity to earn wages, other benefits of integrated employment include expanded social relationships, higher job satisfaction, improved self-worth, transferable work skills, and increased self-determination.\textsuperscript{21} Multiple studies indicate that self-determination status is a predictor of quality of life,\textsuperscript{22} and is positively correlated with improved employment, independent living, and community inclusion outcomes.\textsuperscript{23}

ADD has committed $4 million over 5 years to a consortium of five University Centers for Excellence on Developmental Disabilities to lead a self-determination national training initiative, the “National Gateway to Self-Determination.” The purpose of this project is to enable self-advocates, family members, professionals, agencies, and University Centers to “scale-up” efforts that promote self-determination throughout the lifespan and thereby positively affect individual outcomes. One component is a focus on the relationship between self-determination and employment, as self-determination is an essential element for enhancing individual control and involvement in employment, and ultimately job satisfaction and success.\textsuperscript{24} The Self Determination project is providing training related to self-determination, developing evidence-based practices, and supporting the translation of research into practice.

\begin{thebibliography}{99}
\bibitem{22} Murphy, S. T., Rogan, P. M., Handley, M., Kincaid, C., & Royce-Davis, J. (2002). \textit{People's Situations and Perspectives Eight Years After Workshop Conversion}. Mental Retardation, 40(1), 30-40.
\bibitem{24} Ibid.
\end{thebibliography}
Other Administration Activities

Demonstration projects: Later this year, ADD will be investing over $2 million in demonstrations related to improving opportunities for people with intellectual and developmental disabilities to access competitive, integrated employment. These competitive grants will challenge applicants to develop and implement innovative public/private partnerships to improve employment outcomes for individuals with significant developmental and intellectual disabilities, and ensure improved access to integrated employment at competitive wages and benefits for such individuals, with a particular emphasis on assisting two groups: (1) youth and young adults transitioning from secondary or postsecondary school into competitive, integrated work, and (2) adults currently working in non-integrated facility-based supported employment settings to move to competitive, integrated employment settings. More details will be available about these funding opportunities later this year.

Longitudinal Data Collection: Data collection and analysis not only provides clarity, but as the old adage states, “What gets measured gets done, what gets measured and fed back gets done well, and what gets rewarded gets repeated.” For over 20 years, ADD has supported the Institute for Community Inclusion at University of Massachusetts Boston to collect and analyze data on the nature of day and employment services for individuals with intellectual/developmental disabilities; the Institute’s Director, Bill Kiernan, will also testify today. This project has contributed greatly to our nation’s comprehensive understanding of the factors that influence employment outcomes at every level -- individual, service provider, state and federal policy level.

Research shows a correlation between states that are collecting data from multiple sources, including employment outcome data collected at the individual level, and higher percentages of individuals in integrated employment. Frequent data collection at the individual level creates regular interaction between the state ID/DD agency and providers, helps providers take an active role in working towards a shared goal of increased employment by giving the entities who are implementing activities a sense of ownership in the goals, provides information about training and technical assistance.

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needs on a timely basis, and can be used for better accountability with providers. The very process of the data collection efforts at the state level helps to improve employment outcomes in states.26

**Community Living Initiative:** ADD is an important partner, along with the Social Security Administration’s Office of Employment Support and Ticket to Work Programs and the CMS Disabled and Elderly Health Programs Group, in the Community Living Initiative Employment Workgroup, led by the HHS Office on Disability. The workgroup goals include the development of options for workers with disabilities and/or chronic conditions to gain wraparound home and community-based services and supports to maintain employment, as well as to provide further clarification to stakeholders on how federal policy and programs can help people with disabilities find and maintain competitive employment.

In closing, I leave you with a quote from a woman with a developmental disability, Ms. Susan Willis, who shared this insight with ADD as part of our recent listening sessions, “When meeting someone new, we almost always ask, ‘What do you do?’ A person’s work seems to define who he or she is. It certainly gives people, especially those with disabilities, a sense of self-worth and confidence. With employment comes some level of self-sufficiency, and with that—-independent living. Without a full or part-time job at reasonable wages, none of this can be realized.”

The Administration on Developmental Disabilities and the ADD network are striving to improve opportunities for individuals with intellectual and developmental disabilities to access competitive employment in integrated community settings.

Thank you. I am happy to take any questions you may have.

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