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Good afternoon, I would like to thank the members of the Congressional Down Syndrome Caucus as well as the Board and members of the National Down Syndrome Society for this invitation to participate today. My name is Dr. William E. Kiernan. I am the director of the Institute for Community Inclusion, a University Center of Excellence in Disabilities that is located at the University of Massachusetts Boston and Children's Hospital Boston. I am honored to be here to talk with you about the state of employment for individuals with intellectual disabilities.

Just Like You and Me: For most of us the expectation in our early years as well as through our school years was that at some point we would become part of the typical labor force. The end result would be that we would have an income that would allow us to live independently, have social networks, a place to go on a daily basis and be a valued member of society. For persons with disabilities your dream is their dream to be a contributing member of a community, have resources that they can control, be able to have friends and a sense of satisfaction with what they do on a day to day basis. So where are we with helping persons with disabilities reach the American dream? I would like to share with you what the world of work looks like for many persons with disabilities.

The crisis for many persons with disabilities is not unemployment but the consequence of unemployment: poverty, isolation and limitations on options and opportunities. For many persons with disabilities the expectation is not that in one's adult years you will have a job but that the system will care and protect you and that there will be few if any expectations placed upon you and correspondingly few opportunities delivered to you to be part of a typical adult role, being in the workforce having resources and friends. Over the past several decades one's job has not only provided a chance to be at least partially economically self-sufficient but also to have an opportunity to make friends. When there is no expectation that employment is and must be the goal, the end results of education and the movement into adult years is little more than a continuation of a dependent and limited role in society for person with disabilities.

Data Tell the Story: What do we know about the life circumstances of persons with disabilities? Data show that for persons with disabilities the labor force participation rate, that is the number of persons working as part of the total universe of persons of working age, is about one half (36%) the labor force participation rate (70%) of persons without disabilities (American Community Survey, 2007). For persons with intellectual disabilities that rate drops from 36% to 26.8% or about one in four persons with mental disabilities are working out of the total universe

of similar persons. Without employment and the income derived from employment, person with disabilities are poorer than persons without disabilities, more likely to live in poverty and be perpetually dependent upon other. In 2007 about 7.6% of the general population lived below the poverty level while for person with disabilities that percentage was up by a factor of two and one half times or 19.8% and for persons with mental disabilities that percentage again rose to 24.2% (American Community Survey, 2007). Choice, control and self-determination are just words when there are no resources attached to them. It is clear that the vast majority of persons with disabilities do not work and have no earnings through wage payment.

What about those that are working, what types of jobs do they have and how is it going? About 27% of the person with intellectual disabilities who are served through the adult Developmental Disabilities system are working some in typical work settings and others in groups. Wage payments are often limited to minimum wage and the average number of hours worked per week is 27 (ICI 2008). Typical types of jobs are in the building, grounds and cleaning (12%), production, transportation and materials moving (8.5%), service industries (8%) and then construction, office and clerical. Most earn an annual wage that is often below the poverty level with average weekly earnings at \$180 per week and average hours worked per week at 23 to 26 hours for those working in individual jobs where the employer pays the wage. For those working in group employment where a community rehabilitation program pays the wage the average hours worked remains about the same at 23 hours per week but the earnings are considerably lower at about \$103 per week.

For the majority of persons with disabilities who transition from school into the current adult service system, the most frequent option is sheltered employment or non-work activities. When a student exits school and does not have a job, they are often referred to one of the more than 9,000 community rehabilitation providers. These not for profit agencies contracting with the state agencies to serve persons with disabilities offer a range of service including employment, both competitive and sheltered, as well as non-work programs, including day habilitation and day and community services. Of the more than 1.2 million individuals served through this system about 27% are in employment settings in the community, either competitive jobs or group placements, while the remaining 73% are in sheltered employment or non work settings with generally little or no income. Wage payments in sheltered settings are typically below the minimum wage. While there is a growing interest in seeking competitive employment for those individuals served through the community rehabilitation provider system, there has yet to be a year in the past two decades in which the ICI has collected national data that more persons entered integrated or community employment than entered sheltered or non work settings.

So what are some of the Key Factors that impact the Labor Force Participation Rates by persons with disabilities and more specifically intellectual disabilities. The following outlines some of the major issues that persons with intellectual disabilities face as they enter and continue through their adult years. At the core is the lack of expectation among many that students with disabilities and particularly those having an intellectual disability about being able to work. This lack of expectation is not one that begins at gradation but is often reinforced throughout the student's life from health care providers and other professionals, educators and at times family members. Persons with disabilities are one of the few communities of persons in this country

where there is not a clear expectation that employment is the goal and in many instances it is clear that a strategy of care and protection surpasses the goal of employment. We must reverse our expectations and move to a view that employment is not an option but the focus in education as well as adult services.

Transition: In the young adult years there is the movement from school into adult life. As was noted earlier many youth with intellectual disabilities enter the community rehabilitation system going into shelter and non-work settings. For many who enter this service delivery system there is not a clear exit into a real job. If we were to re-conceptualize the final years of the entitlement process to education and considered a different utilization of the 'final four' years of entitlement, from age 18 to 22, we may be able to alter the current pathways to dependence that many students with intellectual disabilities experience. At the age of 18 if the student has not succeeded and it is determined that he or she should remain in school, they are typically enrolled in the same or a similar curriculum, one in which they have already experienced failure. What the student may be entitled to is four more years of a failing curriculum as well as a witnessing of the progression of their classmates through the educational system giving rise to the continuing question 'what about me'.

The literature and research is clear that those students having an employment experience while in school are more likely to be employed in their adult years. More recently there is a growing recognition of the value of having students with intellectual disabilities complete their final years of entitlement to education in a more age appropriate and adult oriented setting such as a postsecondary environment, a community college or institution of higher education. There are an increasing number of two and four year Institutions of Higher Education that are reaching out to and engaging students with intellectual disabilities as part of their transition from high school to adult life. Passage of the Higher Education Act last year will continue to encourage increased utilization of postsecondary setting for students with intellectual disabilities in the coming years.

Alternatives to the traditional education may include participation in postsecondary settings in classes on a non-matriculated basis, field experience in work setting, engagement in volunteer activities such as AmeriCorps programs that can serve as the basis for developing employment related skills and the use of the One Stop Career Centers to support career exploration. Remaining in the classroom is not an effective outcome for the student in their final four years of education.

Competing Federal Policies: The movement from an entitlement setting to an eligibility environment where the student upon graduation may or may not be eligible for services creates uncertainty for both the student and family members. Additionally, at the federal level there are some considerable inconsistencies that the student experiences ranging for documentation of an inability to engage in employment to be eligible for Social Security Benefits to the enrollment in programs that feel that real work is too risky or beyond the individual's ability.

For many young adults and adults with intellectual disabilities the engagement in employment is viewed as a risky behavior by family members in that the earnings may put the individual at risk

for maintaining their Social Security benefits, health care benefits and other benefits (housing subsidies, food stamps and eligibility for certain health and human services). For some the prospect of entering employment is complicated by the myriad of complex rules and regulations regarding earned income and accumulation of assets. While Social Security has attempted to reinforce the entry into employment by persons with disabilities, typically the rules and regulations for these work incentives and the perceived risk to benefits makes entry into employment less desirable. In December 2007 (the most recent available data) there were 6,252,564 SSI recipients with 357,344 or 5.7% working. Of the work incentives available 1,515 Plans for Achieving Self Sufficiency (PASS) were in place, 5,161 used Impairment Related Work Expenses (IRWE) and 2,142 used Blind Work Expenses (BWE). These data, should they be equally distributed across all states, would imply that less than 30 individuals per state used Pass Plans and about 100 used IRWEs. For some the response to the risk of loss of benefits is dealt with by either not engaging in employment at all or in working only up to a specific limit, not having earnings above the substantial gainful activity (SGA) level.

While the impact of earnings on the social security benefits has a direct relationship to the individual, the rules and regulations regarding the reimbursement of services to state through the Centers for Medicare and Medicaid Services (CMS) are equally complex and also penalizing to those states that place a high priority on employment as the service of choice. CMS, a considerable reimbursement vehicle for state agencies, encourages employment of those who are eligible through its waiver system. Again and in the case of Social Security the complexities of the waiver system make it often times unappealing for states to consider including supported employment as a service option under their waiver. For states the complexities of getting supported employment into the state waiver and the use of CMS services to support employment are at best minimally utilized by state agencies. In both the case of SSA as well as CMS there appears to be a clear interest in seeing increased involvement of persons with disabilities in employment yet the current structures of these two agencies serve to inhibit both the individual and state agencies in being aggressive about establishing employment as the goal.

Employment First: Some state Developmental Disabilities agencies have adopted or are considering adopting an Employment First perspective. This would mean that in the planning for services and the allocation of resources the initial focus for persons who are served would be on employment. Such a focus is a clear message that the outcome of the services that the state agency is interested in purchasing from community rehabilitation providers should be employment. While this is a concept that is somewhat new to most states, some 7 to 10 states that belong to the State Employment Leadership Network, a joint project of the ICI and the National Association of State Directors of Developmental Disabilities Services (NASDDDS), are embracing or considering embracing this as a practice in their respective states.

In each case the state's Employment First approach to services means that integrated community employment is the primary or preferred service option. Washington, the state with the most mature set of policies, has adopted an 'employment only' strategy that identifies integrated employment as the only service that will be supported by the state developmental disabilities agency. Support is contingent upon each person being on a path to employment and services are designed to enable people to reach their individual goals.

Not a Job, Any Job but a Job that has a Future; As in the case of the Employment First focus emerging among several states, about seven years ago the Rehabilitation Services system made the decision to not count sheltered employment as a case closure for the individuals served through the public vocational rehabilitation system. This policy sent a clear message that it was not only employment but it was employment in the typical workforce setting that was the desired outcome.

There is a growing concern that the nature of the employment that is achieved and the amount of the earnings will not be sufficient to have persons with disabilities move out of poverty and be self sufficient. There is also recognition that for persons with disabilities the first job is not the last job and that what should be the goal is not a job but a career path with opportunities for advancement in both earnings and responsibilities.

The measures for success should not be how many come off the roles or were 'closed' but rather a reduction in the use of public benefits as the individual increases his or her capacity to be employed and have earnings. It may be time for us to consider outcomes as rates of employment and reduced reliance on public resources and not just closure. It is likely that while many individuals with disabilities, including those with intellectual disabilities, can be part of the workforce, there may be a need to continue to provide assistance over time. It may be time to re-think documentation of success in employment. This will imply that we must consider issues or impacts of earnings on benefits as well as the ability to retain assets as persons with disabilities advance in their careers.

Integration of Services at the State Level: At the state level there are a number of agencies that are engaged in supporting employment of persons with disabilities. These agencies have differing populations that they serve and are often not well coordinated. The primary agency with its major focus on employment of persons with disabilities is the public vocational rehabilitation system. While working under a presumption of employability for all individuals with disabilities, a number of persons who are served by the state developmental disabilities and state mental health agencies are not served by Vocational Rehabilitation. Some of this could be a reflection of funding limitations in the public Vocational Rehabilitation system nationally. While there have been attempts at collaborative ventures, often these agencies work in isolation. At the education level there has been a long standing concern about the limitation in the transition process and that most student with disabilities who exit school, particularly those with intellectual disabilities, do not enter employment but remain in community rehabilitation programs with minimal or no earnings.

It is not just the human services and rehabilitation systems that are providing employment services but on the workforce development side there is an extensive network of One Stop Career Centers. Established under the Workforce Investment Act the intent of this legislation was to streamline the employment and training process for all job seekers. The legislation brought together the Rehabilitation Act with the Employment and Training system in a marriage that has at best been bumpy. Again at the very local level, there have been some clear examples

of where the workforce and the disability system have coordinated to increase the employment opportunities but to date the true potential of WIA has yet to emerge. The need for a more coordinated and focused system with an eye on employment of all job seekers including those with disabilities as well as those who are considered harder to serve is essential particularly given the current demographics of the country.

While the unemployment rate has risen considerably, it is clear to many that the shortage of workers will grow as the older workers age out of the current workforce. We cannot afford to have only one quarter of the potential workforce of individuals with intellectual disabilities remain on the sidelines and not engaged in work for the sake of the economy as well as the individual.

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