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Abstract

The amendments to the Individuals with Disabilities Education Improvement Act (IDEIA) in 2004 reiterate the significance of producing real post-secondary education, employment, and independent living outcomes. However, current employment data continue to show widespread unemployment and very limited access to inclusive community environments and services for adults with severe intellectual disabilities. On the contrary, data from the *Transition Service Integration Model* (Certo, et al., 2003) demonstrate that these recalcitrant problems could be attenuated if two changes are implemented: the transition from school to adulthood components of IDEIA be strengthened to explicitly authorize school districts to subcontract with appropriate private agencies at the point of transition to produce direct-hire, individualized employment and adult living outcomes, and that the federal government amend the Developmental Disabilities Assistance and Bill of Rights Act to provide an entitlement to long-term support, creating a service system which parallels the functions of IDEIA after school exit.

Seamless Transition and Long-Term Support for Individuals with Severe Intellectual Disabilities

Three public systems have the primary responsibility for transition from school to work and adult living for individuals with severe intellectual disabilities: public schools, the rehabilitation system and the developmental disabilities system. In the United States we have had a federal entitlement to educational and related services for individuals with severe intellectual disabilities since 1975, starting with Education of All Handicapped Children's Act (P.L. 94-142) and its current amended version, Individuals with Disabilities Education Improvement Act (IDEIA) of 2004 (P.L. 108-446, HR 1350). However, there is no entitlement to services after the age of 21. This makes it excessively difficult for this population to receive the long-term support needed to take the skills developed for more than 18 years, through public funding of school-based services, and build a reasonable adult life. This lack of cohesive publicly funded services in adulthood is a wasteful public policy gap since most individuals with severe intellectual disabilities are capable of working and participating in typical activities in their communities as adults, but only when accompanied by long-term support (Brown, Shiraga & Kessler, 2006).

The purpose of this article is to propose two national policy shifts that would enable long-term support after completion of public school and could improve the number of public school graduates with severe intellectual disabilities exiting school with stable jobs: (a) public schools should be authorized directly through amendments to IDEIA to enter into contracts for services with post-school service providers to facilitate a seamless transition to adulthood; and, (b) the Developmental Disabilities Assistance and Bill of Rights Act should be amended to

provide a federal entitlement to services for adults which mirrors educational services under IDEIA in order to sustain and expand public school outcomes (Brown, Shiraga, & Kessler, 2006; Luecking & Certo, 2003; NTLS-2, 2008), and make access to supported employment services under the Rehabilitation Act possible by providing funding for long-term support.

These recommended shifts in policy are based on: (a) an analysis of the public school employment outcomes for young adults with severe intellectual disabilities; (b) the lessons learned by the authors implementing the *Transition Service Integration Model* over the last 15 years; and, (c) a critique of the strengths and weakness in selected enabling legislation, in particular, IDEIA, Developmental Disabilities Assistance and Bill of Rights Act, the Rehabilitation Act, Title XIX of the Social Security Act (i.e., Medicaid), and Title XX of the Social Security Act (i.e., income support programs). The remainder of this paper will review each of these areas in detail citing strengths, weakness and recommendations for improvements.

Legislative Support for Transition from School to Work and Community Living

The Current Process for Transition. Since the 1990 amendments to the Individuals with Disabilities Education Act (IDEA) there has been a mandate to incorporate school to post-school transition planning into the Individualized Education Plan (IEP) of each secondary-aged student receiving special education services. In fact, the 1997 amendments to IDEA eliminated the separation between the Individualized Transition Plan and IEP. Implicit in this requirement is the national policy stated in the law that publicly supported education for students with disabilities should culminate in post-school employment and independent living. That is, graduates should be working in direct-hire, individualized jobs, should be able to access stores and services in their communities, and should be attending post-secondary institutions, as needed and appropriate to their career goals. This point is especially relevant for students with severe

intellectual disabilities since public schools function as the post-secondary educational service provider through age 21 for the vast majority.

Rehabilitation's Role. After school exit around the age of 22 (or during a student's last few years in school), the rehabilitation system is required to assist in the process of transition to work. This represents a departure from the responsibilities of schools which are required to focus holistically on many of the needs of individuals with disabilities. The intent of Congress to interrelate public schools and rehabilitation at the point of transition is obvious given that the definition of transition services is almost identical in both the IDEIA and the Rehabilitation Act. Like the IDEIA, funds from the Rehabilitation Act are administered by the Executive Branch in the U.S. Department of Education through the Rehabilitation Services Administration (RSA). States submit annual plans which secure funds and contractually bind them to follow the mandates of the Act. However, the Rehabilitation Act differs in one very significant way from the IDEIA; it is not an entitlement. It is "eligibility-driven" which in this context means that services only are provided if funds are available. Thus, it is possible to be eligible and not receive services due to lack of funds.

The relevant mechanism for assistance for adults with severe intellectual disabilities from the rehabilitation system under this act is through supported employment services which are reserved for individuals with the "most significant disabilities." The purpose of supported employment services is to provide assistance to transition people with the most significant disabilities into competitive employment. However, if long-term support is needed, it must be provided by another source other than the rehabilitation system, and that source needs to be identified prior to receiving services from the rehabilitation system. The inherent problem in funding a short-term employment service predicated on another funding source for long-term

support for people with severe intellectual disabilities should be apparent. Specifically, the very people for whom this service is intended are individuals who need support indefinitely to maintain employment. Further, since there is no existing universal federal or state entitlement to services for adults with severe intellectual disabilities which could provide a stable source of long-term funding, it is extremely difficult for individuals with severe intellectual disabilities to access supported employment services from the rehabilitation system (e.g., Mank, 1994; Butterworth & Gilmore, 2000; Migliore & Butterworth, 2008).

Developmental Disabilities' Role. The other public system that should provide services for individuals with severe intellectual disabilities as they exit school is the developmental disabilities system. The definition of severe intellectual disability in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 explicitly underscores the need for lifelong assistance, yet ironically, there is no federal entitlement to services for such adults under the Act. This Act is administered by the Administration on Developmental Disabilities (ADD) within the Department of Health and Human Services. The Act authorizes ADD to manage the following functions: (a) fund councils on developmental disabilities in each state; (b) fund Protection and Advocacy agencies within each state; (c) fund university-based Centers for Excellence in Developmental Disabilities in each state; (d) fund an annual discretionary grant competition, Projects of National Significance (CFDA 93.631); and, (e) fund a national network of Family Support Programs.

What is missing in this mix is funding for direct services. Indeed, at the federal level there is no single operating division of the Executive Branch that defines and financially supports services for adults with severe intellectual disabilities on either an entitlement or an eligibility basis. States attempt to fulfill this role through their departments of developmental disabilities.

However, there only is one state, California, whose legislation supports an entitlement to services for this population. In every other state, services are determined by state laws and are eligibility-driven, just like the rehabilitation system. Consequently, service denial and long waiting lists are common (Kitchener, Ng, & Harrington, 2003; Larson, Lakin, & Huang, 2003; McGaughey, Kiernan, McNally, & Gilmore, 1995).

Role of Centers for Medicare and Medicaid Services. Although there is no federal system that mandates and funds services for adults with severe intellectual disabilities, state departments of developmental disabilities can access some federal funds for services through the Centers for Medicare and Medicaid Services (CMS) within the Department of Health and Human Services. Unfortunately, CMS funds tend to be categorical, highly prescriptive and capped at low funding levels. This makes them hard to access for long-term support of daily services. Consequently, this option does not result in universal access to services that parallel the significant level of assistance provided for school-aged individuals under IDEA.

The historical roots of services through CMS (formerly the Health Care Financing Administration) lie in its legislative mandate to support institutionalization for people with the most severe intellectual disabilities under Title XIX of the Social Security Act, Grants To States for Medical Assistance Programs (i.e., Medicaid). CMS was the primary source of funding for the large network of state institutions for this population that operated in the United States. Although the number of large state institutions has decreased significantly over the years since 1970 (Prouty, Alba & Lakin, 2008), the assumptions under which an individual can access services through CMS remain grounded in eligibility issues that relate to institutionalization. CMS is the "provider of last resort," and, as such, funds services for the most critical or highest risk cases with risk defined by severity of medical conditions or functional limitations in

activities of daily living.

In an attempt to introduce more flexibility into the use of Medicaid funds and services, in 1981 Congress created Section 1915(c), a waiver program option within Title XIX that allowed home and community-based care for specific populations that included people with severe intellectual disabilities (Miller, Ramsland, & Harrington, 1999). This program became known as 1915(c) waivers or Home and Community-Based Services (HCBS), and it allowed the provision of a wide array of services, including employment services, if the intent was to prevent institutionalization. By 1997 there were 221 waiver programs in operation, each state operated at least one (Miller, et al., 1999) and the largest portion of recipients were individuals with developmental disabilities, the majority of whom constituted individuals with severe intellectual disabilities (Kitchener, Ng & Harrington, 2003). The specific services covered under a waiver program were articulated by the states in their waiver application to CMS.

Although Medicaid is an entitlement program like IDEIA, and under 1915(c) waiver programs can include funds for employment services and community living skills training, these waivers do not result in universal access to adult services for three reasons: (a) they focus on those individuals most at risk of institutionalization; (b) states are required to target waivers to specific subpopulations or geographic regions, reducing the number of people covered; and, (c) states are required to specify the total number of individuals to be served under the waiver and cannot exceed that total. All three reasons are based on assumptions that relate to containing costs. Although Medicaid is a statewide entitlement, and must be applied uniformly to all eligible individuals, the 1915(c) waivers work in the exact opposite way by focusing on particular groups or areas with set limitations on access to services. Two notable examples of the limited access common to HCBS programs are Wisconsin which had 20,046 individuals on a

waiting list for HCBS in 2002, and Texas which had 74,224 individuals on waiting lists that same year (Kitchener, Ng & Harrington, 2003). Furthermore, if an individual is exiting public school with a stable job, that individual is considered less at risk of institutionalization from the perspective of 1915(c) waivers, placing them in a lower priority group for waiver services.

Postschool Outcomes Have Not Met Legislative Intent

Pervasive Unemployment. Despite the various mandates and funding mechanisms, the low employment rate of people with severe intellectual disabilities and the consequent social and economic marginalization are significant social problems (Migliore & Butterworth, 2008). Securing and maintaining employment continue to be the areas that result in the largest negative discrepancy between those with severe intellectual disabilities and those without (Harris, 2000). Eight percent of those with severe intellectual disabilities were employed, in comparison with 81% of those without disabilities (Harris, 2000). More recent data show these figures are essentially unchanged (National Organization on Disability, 2004).

This large discrepancy in rates of employment has persisted despite many efforts to reduce it. In the 1980's, the federal government began a more concentrated focus on employment outcomes (Will, 1984), yet segregation in facility-based programs still is the norm for adults with severe intellectual disabilities. Facility-based and non-work services comprised 77% of all Mental Retardation/Developmental Disabilities services for people with severe intellectual disabilities in 1999 (Dreilinger, Gilmore, & Butterworth, 2001), and Metzel, Boeltzig, Butterworth, Sulewski, & Gilmore (2007) report this number at 74%, currently. Rizzolo, Hemp, Braddock & Pomeranz-Essley (2004) report that in 2002 state Mental Retardation/Developmental Disabilities (MR/DD) agencies served approximately 365,000 individuals with severe intellectual disabilities in day activity or sheltered employment programs.

By comparison approximately 118,000 people were served by these agencies in supported or competitive employment. This represents a 3:1 ratio of non-competitive to competitive work outcomes for individuals with severe intellectual disabilities served by MR/DD agencies (Wehman & Revell, 2005).

More importantly, Migliore, Mank, Grossi & Rogan (2007) reported that a majority of surveyed participants with severe intellectual disabilities (N = 210) working in sheltered workshops would prefer outside employment (N = 202; 80%). Both families and staff of participants were confident that these participants could work outside of segregated workshops with appropriate support. This situation has generated an income gap that has remained high for decades. Adults with severe intellectual disabilities are three times more likely than their nondisabled peers to live in poverty with household incomes of \$15,000 or less (Harris, 2000; Butterworth & Gilmore, 2000).

Post-School Employment Outcomes. The employment outcome of recent public school special education graduates with severe intellectual disabilities is just as low as that of their older counterparts (Horvath-Rose & Stapleton, 2003). Despite a quarter century of attention in legislation, program and model development, post school success for these individuals continues to significantly lag behind the general population. In the 1980's, Wehman, Kregel, and Seyfarth (1985) cite that an estimated 12 percent of the students with severe intellectual disabilities had worked in the five years following public school. In the original National Longitudinal Transition Study (NLTS), Blackorby and Wagner (1996) found that only 13% of students who exited school exclusively by aging out of the system at 22 years old (i.e., typical exit age of students with severe intellectual disabilities) were competitively employed two years after high school. This rate rose to 25% three to five years post-graduation (National Council on

Disability, 2000). In the follow-up NLTS-2 study, data for students who exited public school with mental retardation from the 2003 national sample show that this rate had a modest increase to 25% employed (NTLS-2, 2003), two years after school exit, and the 2005 national sample shows an even better increased employment rate two years post-school exit of 59% (NTLS-2, 2008). Although mental retardation assumes a broader population than individuals with severe intellectual disabilities, and this follow-up study does not differentiate whether the employment is sheltered or competitive, NLTS-2 data remains the best available current benchmark for comparison with the employment results for graduates with severe intellectual disabilities. The result of these poor outcomes is that young adults in this group are at high risk for poverty due to their lack of employment (La Plante, Kennedy & Turpin, 1996; Dreilinger, Gilmore, & Butterworth, 2001; Migliore & Butterworth, 2008). Too many rely solely on cash benefits from federal income support programs, which alone are substantially below the poverty level (National Council on Disability, 2000).

Ineffective National Transition Policies. The low employment rates and earnings, and increased poverty and reliance on publicly funded income support, invite questions about federal policies that have been directed toward alleviating these problems. These outcomes are inconsistent with transition mandates explicit in IDEIA and the current amendments of the Rehabilitation Act of 1998 and with the employment and inclusion tenets in the Americans with Disabilities Act of 1990, the Ticket To Work and Work Incentives Improvement Act of 1999, and the Developmental Disabilities Assistance and Bill of Rights Act, as amended in 2000.

Students with severe intellectual disabilities, more than any other disability group, tend to graduate without jobs and into segregated settings (McGaughey, et. al., 1995; Mank, 1994; Wehman & West, 1996; Dreilinger, Gilmore, & Butterworth, 2001; Metzel, Boeltzig,

Butterworth, Sulewski, & Gilmore, 2007). However, this same group also has seen increased participation in integrated general educational experiences through school-based full-inclusion programs (Fisher, Sax, & Pumpian, 1999; Hunt, et al., 2003; Hunt, et al., 2004; Hunt, et al., 2002; Hunt & McDonnell, 2007). The result is that more students are experiencing inclusion and work-based learning during their school years, yet many continue to face unemployment and segregation in adulthood. This situation greatly reduces the value of the effort and money spent on community-based inclusion, job development and other work-based experiences during school years.

An Alternative Service Delivery System for Transition

Service Integration. It is our contention that two major shifts in the current transition service delivery system for postsecondary-aged students with severe intellectual disabilities must occur to make the goal explicit in IDEIA of producing the outcome of direct-hire, individualized employment and inclusion into adult society a reality. First, such students enter their last years in public school, the service delivery model for transition must shift from the public school as sole provider to one based on service integration across multiple systems (Certo, et. al., 2003; Certo, et al., 1997; Certo & Luecking, 2006; Gerry & Certo, 1992; Luecking & Certo, 2003; Owens Johnson, et al., 2002). Specifically, school districts must integrate their staff and resources with those of a community rehabilitation agency, the state rehabilitation system and the state developmental disabilities system prior to graduation to jointly produce meaningful work outcomes and to secure authorization for continued support after graduation resulting in a seamless transition for graduates. Legislative changes that would allow payment for direct services within the Developmental Disabilities Assistance and Bill of Rights Act would enable this authorization of post-school services in all states and thus allow equal access for adults with

severe intellectual disabilities. Through service integration, cooperation among responsible systems in the transition process becomes more interactive, moving from passive consultation to active planning and sharing of responsibility and resources at the same point in time.

Total Immersion in Community. Second, a fixed school site must be eliminated for postsecondary-aged students, aged 19 to 21 years old with severe intellectual disabilities for whom high school is no longer age-appropriate. Similarly, the locus of services must shift to a total community immersion approach with students accessing preferred work and off-work activities on a full-time basis in natural functional community environments so that the actual outcome of transition is the students fully included in their communities with direct-hire, individualized employment and with the skills and social supports in place needed to access stores, services, institutions of higher education, and recreation and leisure activities and facilities. Further, they should be served in their final school year by a community rehabilitation agency under subcontract with the public schools and exit school with services authorized by the state rehabilitation and developmental disabilities systems to continue support by the same agency (Certo, et. al., 2003; Certo, et al., 1997; Luecking & Certo, 2003; Certo & Luecking, 2006), so that the transition is seamless. In short, the day after graduation should look no different than the day before for the individual exited the school system; that is, there would be no break in services for graduates.

One Solution to Poor Postschool Outcomes: The Transition Service Integration Model. In 1994, the senior authors, along with many colleagues (e.g., Certo, et. al., 2003), set out to build a new service delivery model that would produce a seamless transition and would reverse this recalcitrant unemployment problem. It would contain two key components: a curricular shift to a total community immersion approach to direct services (Certo, Wade & Lura, 2002), and a

reconfiguration of the approach to service delivery that would connect and integrate the school and post-school systems and produce a seamless transition. It was assumed that together, these components would increase the outcomes of a normalized, integrated lifestyle as well as direct-hire, individualized jobs. That is, jobs where employers hire and pay prevailing wages to the individual employee; that are developed based on individual preferences and skills; with attention to employee support; and, the needs of the employers. These components would meet both the letter and intended purpose of the IDEIA and the Rehabilitation Act, and this service delivery model was referred to as the *Transition Service Integration Model (TSIM)*. A brief outline of the core aspects of the systems-change and direct service curriculum components is listed below (for a more detailed discussion see, Certo, et al., 2003).

Systems Reconfiguration for Direct Student Services. In order to integrate public schools with post-school systems, an intermediary was needed whose staff could work with students before and after school exit. Private non-profit agencies, referred to under the model as, "hybrid agencies," approved to provide services to adults with severe intellectual disabilities by both the rehabilitation and developmental disability systems were identified to fill this role.

As part of the reconfiguration of the systems, public schools subcontracted services directly to these private non-profit hybrid agencies that focused on employment, independent living and adult life to serve students who were in their last year of school to meet Individualized Education Plan (IEP) goals in the areas of customized competitive employment and adult community living. However, the schools maintained a teacher of record to provide oversight and ensure IEP goals were met. These pending school graduates received services in their last year of school from the hybrid agency under a total community immersion approach with daily instruction in functional work and off-work community environments and with no fixed school

site (Brown, et al., 1983). As such, they experienced and adapted to the post-school approach to services prior to school exit, helping to better inform their choice of continuing such services after graduation.

Coordinated Oversight. Another key component responsible for integrating these public systems involved monthly meetings with key stakeholders. These meetings included direct service and administrative representatives from the public school, the hybrid agency, selected clients (or family), state rehabilitation and developmental disabilities systems, and were designed to review progress in achieving work and off-work IEP goals through the receipt of direct services from the hybrid agency. They also served to secure agreement and subsequent service authorizations to ensure that the funding for long-term adult work and off-work support was secured prior to school exit from the state rehabilitation system and the developmental disability system. Having these agreements in place prior to school exit was critical in ensuring that the transition would be seamless.

Seamless Transition. At school exit, graduates experienced a seamless transition by continuing to work in the same customized competitive employment positions and participating in the same integrated community living activities established prior to exit, with ongoing support from the same non-profit hybrid agency as long as they remained satisfied with the services. This resulted in a seamless transition from school to post-school. As such, the day after graduation was no different than the day before for these individuals, as the ongoing support to sustain employment and community integration remained with the same agency and was secure. Retaining integrated jobs and community living activities, and the necessary long-term adult system support, via a seamless transition, was the core outcome obtained through the simultaneous application of both the reconfiguration of the systems and the direct services, total

community immersion curriculum component of TSIM.

Outcomes. Participant outcomes in the area of employment and seamless transition, collected at the end of each school year (i.e., point of school exit) during the first five years of model implementation (i.e., Academic Years '98 to '02), verify that *TSIM* model was effective in helping students find and maintain direct-hire, individualized employment (Luecking & Certo, 2003). During this period, the model was implemented in 12 school districts in California and two in Maryland. These districts comprised a heterogeneous group of large urban, small suburban, county-wide, rural, and multi-district consortia school systems. Under *TSIM*, 293 students were served during this five year period while in their last year of public school at the age of 21; of those individuals, 261 (i.e., 89%) exited school seamlessly with the continuation of their support provided by the same hybrid agency; and, 177 (i.e., 60%) exited school with a direct hire job at a prevailing wage of \$6.62 per hour for 14 hours of work each week on average. Further, maintenance data collected from selected sites at the end of the third year of model implementation showed that among the first 103 graduates, 93 (i.e., 90%) still were being served by the same private non-profit agency, and 66 (i.e., 71%) were employed.

These data compare to national employment statistics quite favorably. In the 2003 NLTS-2 sample, only 25% of students with mental retardation were employed two years after exit, 35 percentage points below the *TSIM* average. The 2005 sample from NTLS-2 shows a much better outcome with 59% students with mental retardation employed two years after exit; one percentage point below the *TSIM* average. However, the NTLS-2 sample is broader than the population of students with severe intellectual disabilities served under *TSIM*. NTLS-2 does not differentiate the surveyed population based on level of intellectual disability, and does not differentiate between sheltered and integrated competitive employment. Thus, although it is

difficult to make an exact comparison between NTLS-2 and *TSIM* data, this suggests that a service integration approach such as that created through *TSIM*, has the potential to significantly improve current levels of community integration and employment outcome data for all students with severe intellectual disabilities.

Continuing Challenges To Model Implementation

The potential advantage of shifting the locus of service prior to graduation from the local public school to a long-term, post-school provider, coupled with securing authorization for continued support after graduation is obvious. However, in spite of these positive data, it can be difficult to convince school district administrators to implement this service delivery model because it means that they need to conduct business differently; a common hurdle in any service integration effort (e.g., Gerry & Certo, 1992).

Unlike the rehabilitation and developmental disability systems, which routinely enter into contracts with providers to secure services for consumers, public schools hire their own direct service personnel. In our experience with a wide variety of districts, subcontracting was reserved for extreme situations where the school system was unable to cope with the needs of its most challenging students. Paying an outside agency to provide basic educational services raised many concerns among public school administrators and teachers during the development of *TSIM*. Legislation which supported subcontracting would greatly improve the perception of legitimacy for this important mechanism.

Another more serious problem related to the lack of long-term public support: there is no national entitlement to services for adults with severe intellectual disabilities. As discussed previously, among the two logical public systems to support individuals with severe intellectual disabilities after they exit school, neither the federal rehabilitation system nor the state

developmental disability system presently provides an entitlement to services, and there is no federal developmental disability service system, only an eligibility-driven federal rehabilitation system and a fragmented network of circumscribed services through Medicaid. This means that even if schools are able to successfully implement curriculum and special education services that promote individualized employment and full community immersion, the support to maintain these services effectively end at school exit in the absence of available and well planned linkages.

Creating New Legislation To Plug This Policy Gap

Based on our experiences with positive results from *TSIM* (e.g., Luecking & Certo, 2003), we contend that changes in legislative policy are needed in IDEIA, the Rehabilitation Act, the Social Security Act and the Developmental Disabilities Assistance and Bill of Rights Act to increase and maintain positive outcomes at the point of transition from school. Each of these will be reviewed separately.

IDEIA. The lynch-pin for creating a seamless transition under *TSIM* was the contract between the local public school and the private non-profit agency that provided services to adults with severe intellectual disabilities. IDEIA needs to be strengthened to explicitly encourage school districts to subcontract with private non-profit agencies at the point of transition to produce direct-hire, individualized employment and adult living outcomes and to add emphasis to the need to secure authorization for long-term support for individuals with severe intellectual disabilities as they exit public school. The current amendments to IDEIA only suggest the possibility of subcontracting in this situation; the language needs to be strengthened.

From our perspective, subcontracting with a hybrid agency clearly constitutes, “adult services” and “related services,” and serves as an interagency linkage between public schools

and adult system-funded private agencies that focuses on a “results-oriented process” which “facilitate[s]... movement from school to post-school activities” for pending public school graduates (i.e., IDEIA, Sections 602 and 614). Including more explicit language that endorses for this method of subcontracting as a service integration mechanism in the next reauthorization of IDEIA would be a substantive step toward enabling the successful policies and practices suggested by our data, and a growing convergent body of evidence (e.g., Baer, et al., 2003; Brown, Shiraga, & Kessler, 2006; Migliore, Mank, Grossi, & Rogan, 2007; Wehman, Revell, & Brooke, 2002) to become a wide-scale reality, and would open the door to real public school outcomes for students with severe intellectual disabilities at the point of transition to adulthood.

Further, as a policy matter and in order to institutionalize a results-oriented process in transition services, it is important to counter the tendency of school districts to see their legal responsibility merely as preparation for outcomes to be attained sometime in the future after school exit by others. Otherwise, there will be little attention paid to the ultimate outcomes of employment and independent community life for youth with severe intellectual disabilities. Moreover, current mechanisms to reward, or punish, school districts based on student achievement on standardized tests creates another tendency for school administrators to ignore the accomplishments of youth whose performance cannot be measured in this fashion. Provisions must be considered in both policy implementation and in future legislation that alternatively gauge preparedness for post-school adult success. For youth with severe intellectual disabilities this means developing an employment record during secondary school years that can be supported and maintained by linkages with post-secondary service providers and systems after school exit. Wehman, Revell and Brooke (2003) suggest the key to breaking the existing cycle is to concentrate on youth and young adults aged 16-25. They suggest the

cycle can be broken here as more young adults with severe intellectual disabilities refuse to go to post-school segregated programs, and their families or guardians refuse to accept these programs as a base for services. States and local school districts will be pushed to create new service agencies that provide supports for people with severe intellectual disabilities working in direct-hire, individualized employment (Wehman, Revell, & Brooke, 2002).

Developmental Disabilities. It is astonishing and significantly short-sighted to note that we have a federal entitlement through the Medicaid Program of Title XIX of the Social Security Act that pays half or more (depending on the established state reimbursement formula) of the costs to place an individual with a severe intellectual disability in a large state institution, somewhat smaller intermediate care facilities for people with mental retardation/developmental disabilities (ICFs-MR/DD), or provides residential service through HCBS waivers, yet we have no comparable federal support that pays for universal access to adult services provided during the normal work day. Adult services for individuals with severe intellectual disabilities, such as job development, employment support, support to access and learn to use stores, services, volunteer activities, leisure and recreational activities (i.e., "day services"), which enable those same individuals to learn how to live and work in their home communities are not routinely supported by any one federal or state public source, as they are for school-age students. The irony of this situation is apparent when one acknowledges the huge reversal from routine institutionalization to community living for this population that has occurred in the last 30 years (Prouty, Alba & Larkin, 2008). Certainly, through the 1915(c) HCBS waiver programs, some "day services" are provided to narrowly defined sub-populations within the larger group of adults with severe intellectual disabilities. However, universal access which mirrors the entitlement of IDEIA does not exist and is not reinforced at the federal level with targeted legislation.

This paradox is emphasized when one considers the costs of large state institutions or smaller ICF-MR/DDs. Prouty, Alba and Lakin (2008) report that the average cost of institutionalization in large state institutions (i.e., facilities with more than 15 residents) in FY 2007 in the U.S. was \$176,226 for each individual with a severe intellectual disability or \$482 per day, and that 36,650 individuals were institutionalized nationally. Simply multiplying the number of residents by the average annual cost, you get a total annual public investment of \$6.5 billion. In addition, Prouty, Alba and Lakin (2008) report that the total combined state and federal Medicaid cost for ICFs-MR/DD (i.e., facilities with an average of 15 residents) in 2006 was \$12.5 billion (related 2007 cost data not yet available) or \$127,134 per resident for 96,527 residents. Combined, this is an expenditure of \$19 billion; a very large sum.

In comparison, the cost of services under Medicaid HCBS waivers in 2007 was \$41,387 per person (Prouty, Alba and Lakin, 2008), and that there were 501,489 individuals served under these waivers with a total expenditure of \$20.7 billion. Burwell (2003) reports a similar expenditure for HCBS in 2002 of \$25 billion, equaling 30% of the total costs of Medicaid services that year. This finding is consistent with the shift from large institutions to services in much smaller community settings; a drop of 84% since 1977 with only 14% of this population institutionalized in 2007.

In California the state Department of Developmental Services (DDS) pays a maximum of approximately \$87 per day for each individual receiving "day services," as described above. Assuming the maximum allowable 255 day service year, this equals \$22,185 per individual served. According to ADD, there are 4.5 million individuals in the U.S. who have developmental disabilities. Of that population approximately 60%, or 2.7 million are adults ranging in age from 20 to 64 years old. Providing integrated employment and community

inclusion "day services" for this population at the maximum rate used in California (a state with one of the highest costs of living in the country) would equal \$59.9 billion. Adding the residential services cited above to this figure you get a total public expenditure of \$99.6 billionⁱ. However, since some of the funds currently being expended under HCBS program pay for "day services" for this population, the total new cost would be slightly lower. To put this figure of \$59.9 billion in the context of the federal budget, this would equal 9%ⁱⁱ of the \$644.59 billion FY08 Congressional appropriation for the U.S. Department of Defense (GovTrack.us. H.R. 3222--110th Congress, 2007). In addition, it is important to remember that Medicaid funds are matched by the states at a rate of approximately 50%, so this figure of \$99.6 billion would be split almost equally between states and the federal government, if Medicaid was the funding source.

Although IDEIA specifies that the U.S. Department of Education should make grants to states for special education services that equal 40% of the average per pupil costs of elementary and secondary education (IDEA, Part B, Section 611), Congress has never appropriated the funds required to meet that figure. Historically, OSEP has provided approximately 12% of the total funds needed to serve students with disabilities (Kafer, 2002; Horn & Tynan, 2001). If the Developmental Disabilities Assistance and Bill of Rights Act was amended to mandate integrated employment and community inclusion "day services" at reimbursement rates similar to IDEIA of 12%, this would amount to a federal expenditure of approximately \$7 billionⁱⁱⁱ. This would be an 17.6% increase over the current federal and state expenditure through Medicaid of \$39.7 billion^{iv}, or a 35%^v increase in the federal contribution. Finally, to put this in federal budget perspective, \$7 billion would equal 1% of the FY08 Defense Department appropriation. Although this only would cover 12% of the cost of "day services," like IDEIA funds, it would

provide a strong incentive for states to participate. Certainly, it is never popular to advocate for an entitlement which would increase both state and federal costs, regardless of the strength of the economy. However, these authors would like to point out that the parents and advocacy groups who were successful in getting Congress to pass the federal entitlement to education for all students with disabilities in 1975 also were told that such an entitlement was an impossible goal. Luckily for students with disabilities, they did not let that stop them.

Rehabilitation Act. The inherent contradiction of providing supported employment services to people who have the "most significant disabilities"^{vi} under a time-limitation and under an expectation that independence on the job, that is, the elimination of support, equates with a successful job placement, has to change. As cited earlier, people with severe intellectual disabilities can work, as long as they can have on-going support. The goal of supported employment services under the Rehabilitation Act should be to develop and stabilize a job, regardless of the level of support required. Rehabilitation should provide supported employment services freely to individuals with severe intellectual disabilities under the Presumption of Eligibility and Presumption of Benefit which already exist in the Act (Section 102a), and simply transition those individuals to long-term support through the entitlement to services established under the amendment to the Developmental Disabilities Assistance and Bill of Rights Act recommended in this paper.

Social Security Administration. The data of Brown, Shiraga and Kessler (2006) clearly demonstrate that long-term maintenance of individualized direct-hire jobs for individuals with severe intellectual disabilities can be achieved. However, their data also demonstrate that the limitations on income and asset accumulation set by the Social Security Administration under the Supplemental Security Insurance (SSI) and Social Security Disability Insurance (SSDI)

programs established by Title XX of the Social Security Act stand in the way of full-time and part-time employment at higher rates of pay. Despite the Social Security Administration's efforts to encourage employment, SSI and SSDI programs appear to perpetuate poverty, rather than assist individuals with severe intellectual disabilities to stay employed and improve their incomes (Wehman, 2006).

There are several problems associated with SSI and SSDI that result in disincentives to employment or increased earnings. One issue is limitations on income and asset accumulation. Although the Social Security Administration has implemented a number of work incentives and income exclusions for both programs, such as Trial Work Periods (TWP), 1619 (a), Plans to Achieve Self-Support (PASS Plan), Impaired Related Work Expenses (IRWE), earned and unearned income exclusions, Impaired Related Work Expense (IRWE), earned and unearned income exclusions, or Student Earned Income Exclusions (SEIE), and they have tried to make the programs responsive to changes in an individual's disability status and employment circumstances, their efforts have created a system that is difficult, if not impossible, for people with significant disabilities to access, understand and/or manage without the support of a trained benefits specialist (Wehman, 2006). People struggle to apply and learn the program requirements. Once receiving benefits, many people struggle to understand or utilize the exclusions and incentives and are reticent to earn wages that will jeopardize their safety net.

Second, eligibility for SSI or SSDI also meets the eligibility requirements for Medicaid in most states (Social Security Administration, 2008). The mere threat of losing Medicaid coverage by becoming ineligible for SSI or SSDI is a significant disincentive if an individual with severe intellectual disabilities wants to increase their income. However, section 1619 (b) of the Social Security Act and the Medicaid buy-in programs available for SSDI recipients, allow an

individual to work while continuing to maintain their Medicaid benefits for extended periods of time. Unfortunately, despite the Social Security Administration's concerted efforts to eliminate this disincentive it remains an issue. Methods used to establish and retain eligibility for Medicaid are extremely complicated and vary from state to state. Many people on SSI and SSDI are uninformed of these policies or programs available to extend healthcare (or cash) benefits, and, the rules and reporting process is onerous for anyone, let alone someone with a severe intellectual disability.

It is difficult to find benefit specialists who can evaluate and explain how returning to work will impact an individual. In recognition of the difficulty involved in transitioning into employment, in 2007 the Social Security Administration began to train Community Work Incentive Coordinators (CWIC's) to provide benefits counseling for SSI and SSDI recipients who were interested in working. However, the number of CWIC's being trained and currently available does not match the need. At a minimum, to truly encourage people to work, the Social Security Administration should create an internal, benefits advising or case management system to support those people who are transitioning into employment at all local field offices. These benefits counselors could analyze each recipient's situation, explain and help guide people through the changes that will occur, and encourage them to develop employment plans that will eventually lead to financial independence. People with severe intellectual disabilities may be reticent to talk with the Social Security Administration about returning to work for fear of losing their benefits. Having studied these incentives, it is our opinion that once they realize that a wide variety of incentives and exclusions are available and that the operating principle which governs these incentives is to assist them to access supports and resources needed to transition to employment and self-sufficiency, people will be more likely to utilize the service. And, it will

help dispel the common misperception that the goal of the Social Security Administration simply is to save tax dollars by pulling their benefits.

Another more preferable way to encourage people to work would be to simplify the programs and processes. Wehman (2006) suggests, SSI and SSDI for individuals with severe intellectual disabilities should operate like the Old Age Survivors Insurance (OASI) program where after the age of retirement, the retiree's income is not part of the eligibility determination for OASI. Therefore, limitations on income are eliminated. SSI pays a maximum of \$637 per month or \$7,644 annually. Maintaining SSI and working for 10 hours per week, for example, would not lift the worker out of poverty, but it would substantially increase their annual income, maintain their access to health care and create an incentive to try for more hours on the job, or a better paying job altogether.

Combined with new incentives under IDEIA for school systems to begin contractual collaboration prior to school exit for these youth, correlated changes in an entitlement to adult services through a federal developmental disabilities service system, and improved access to Supported Employment, described above, these changes would offer a powerful prescription for the kind of post-school employment success that a long history of legislation and policy has attempted to influence. If Congress would follow this prescription, seamless and successful transition with better employment and community inclusion outcomes, consistent with current legislative intent would be the result for far more public school graduates with severe intellectual disabilities than currently is the case.

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ⁱ i.e., \$6.5 billion/large institutions + \$12.5 billion/ICFs-MR/DD + \$20.7 billion/HCBS + \$59.9

billion/DD "day services" = \$99.6 billion

ⁱⁱ \$59.9 billion/\$644.59 billion = 9%

ⁱⁱⁱ i.e., 12% x \$59.9 billion = \$7 billion

^{iv} \$6.5 billion/large institutions + \$12.5 billion/ICFs-MR/DD + \$20.7 billion/HCBS = \$39.7 billion

^v i.e., \$7 billion divided by [$\$39.7 \times .50$] = 35%

^{vi} Rehabilitation Act's term that equates with severe intellectual disability.