

Editorial

In this final issue for 2013 of the Journal, I am extremely pleased to introduce a cutting edge paper by Dr. Gary Siperstein and his colleagues who present the first national study, funded by the Centers for Disease Control, that investigates the labor participation rate and level of employment of individuals with intellectual disabilities. Through a collaboration with the Gallup Survey organization 341,000 households were screened by Gallup and eventually a nationally representative sample of 1017 people was queried about their employment status. The importance of a study such as this cannot be underestimated since there has not been a well designed national study exclusively related to employment rates for the those with intellectual disabilities. Before summarizing the meaning of this work, I think it will be helpful to underscore some of the critical issues we face in the U.S. with the challenge of unemployment for persons with intellectual disabilities.

Placement into segregated day programs and sheltered workshops cannot be an acceptable end point for individuals with intellectual disabilities (Bates-Harris, 2012; Gore, 2011; Kiernan, Mank, & Wehman, 2011; Rogan & Rinne, 2011). Although segregated day programs may be the only placement option for some, most individuals with intellectual disabilities aspire to competitive employment as their first career option and work to achieve that (Luecking, 2009; Wehman, Inge, Revell, & Brooke, 2007). Employment specialists must help these aspirations become realities. If people with disabilities do not view themselves positively and have high vocational aspirations, then the expectations of advocates, family members, friends, and others working on their behalf will reflect that position.

Despite national and state policies promoting integrated employment, the majority of adults with intellectual or developmental disabilities (71%) are served in facility-based programs or nonfacility community programs (Braddock, Rizzolo & Hemp, 2010). Migliore, Mank, Grossi, & Rogan (2007) focused on whether or not this gap between policy and prac-

tice is in part attributable to the lack of interest of adults with intellectual disabilities and their families for employment outside facility-based programs. The overwhelming response of workshop clients was clear: “We want competitive employment.” Results were based on the answers given by 210 adults with intellectual disabilities in 19 sheltered workshops, their respective families or caregivers ($n = 185$), and staff members in these workshops ($n = 224$).

Migliore et al. (2007) reported that the majority of respondents would either like employment outside sheltered workshops or at least consider it an option. Moreover, the majority of respondents believed that adults with intellectual disabilities can perform outside workshops, if support is made available if needed. It is noteworthy that the preference for employment outside of workshops is not associated with the severity of the disability.

Unfortunately, numerous barriers exist in attaining employment competence for people with intellectual disabilities. These barriers are societal, programmatic, attitudinal, and physical. Even more critical is the barrier of poverty. Many people with disabilities are poor; they do not have enough money to afford housing, utilities, transportation, or even food (Fremstad, 2009; Parrish, Rose, & Andrews, 2010; Hughes & Avoke, 2010). Without these basic human needs being met, it is next to impossible for someone to embark on a job search.

Another major barrier that must be considered for people with intellectual disabilities is their collective inexperience with gaining control over key events in their lives. The American culture is rooted in a set of values that are strongly tied to power, control, and influence. Bookstores, newspapers, and magazine articles are filled with feel-good stories about self-made millionaires, powerful CEOs of large corporations, and gifted athletes from humble backgrounds signing multimillion-dollar contracts. Americans have a great fondness for these stories because they are about people

who take control of their lives, accept risks, make difficult decisions, set goals, and, most important, become successful.

Historically, individuals with intellectual disabilities have been denied access to the very events that would provide them with the opportunity to take risks, make decisions, and ultimately experience these highly prized American values of power, control, and influence. Furthermore, because of a lack of economic resources or a loss of specific skills, many people with intellectual disabilities are vulnerable and depend on a human services system in which they are stereotyped and stigmatized. Among medical and human service professionals, people with intellectual disabilities are viewed as recipients of services with very little to contribute. As a consequence, systems are created and service practices are institutionalized that contribute to the disempowerment and dependency of people with intellectual disabilities.

Finally, one of the most imposing barriers to employment for people with intellectual disabilities is the potential loss of income assistance and health care through programs administered by the Social Security Administration (SSA) and the Centers for Medicare and Medicaid Services (CMS). The two major SSA disability programs are Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). Although the two have different eligibility criteria, under both programs, individuals with intellectual disabilities must prove themselves to be incapable of engaging in substantial gainful activity (SGA), (Kregel & O'Mara, 2011).

For many individuals with intellectual disabilities, full-time employment with health benefits is not an option because of low levels of job skills, local labor market conditions, limitations in stamina or endurance, or the need to commit substantial amounts of time to personal care needs or treatments. Yet, if they obtain part-time employment, they risk losing cash and other benefits, particularly medical coverage under Medicaid (in most states linked to eligibility for SSI) or Medicare (linked to eligibility for SSDI). This economic disincentive persuades most beneficiaries to limit their earnings to less than SGA or, more commonly, not to enter the labor market at all despite the fact that those utilizing Medicaid waivers can do well in the work (Miller, O'Mara, & Kregel, 2012).

It should be noted that many businesses will rarely admit the real reasons that keep them from hiring people with intellectual disabilities (Hartnett, Stuart, Thurman, Loy, & Batiste, 2011). However, looking behind the excuses given, it is possible that the primary reasons

are concern, fear, or anxiety that people with disabilities cannot work successfully and a general lack of knowledge about what employment looks like for people with disabilities. Luecking (2011) notes that words, concepts, and descriptors, such as *vocational assessment*, *supported employment*, *individualized education program*, *discovery*, and other terms in common usage by disability employment programs and professionals are not understood by employers, who consistently report that interaction with disability employment programs is characterized by both unfamiliar terminology and a lack of understanding of business protocol. In an interesting recent study, Kaye, Jans, & Jones (2011) surveyed human resource professionals to find out the reasons for this reluctance. The principal barriers to employing workers with disabilities are lack of awareness of disability and accommodation issues, concern over costs, and fear of legal liability. With regard to strategies employers might use to increase hiring and retention, respondents identified increased training and centralized disability and accommodation expertise and mechanisms. Public policy approaches preferred by respondents included no-cost external problem solving, subsidized accommodations, tax breaks, and mediation in lieu of formal complaints or lawsuits.

In the Siperstein article, which immediately follows this editorial, the author provides a true scientifically derived benchmark for where we stand in the employment of persons with intellectual disability in 2013. We see, for example, that only 34% are employed and barely 2/3 of them in real work for real pay, the balance are in sheltered employment. While not wishing to divulge too much of this article's findings, I did find one of the conclusions stated especially salient: "For an adult with intellectual disability, it would not be difficult to become discouraged considering the employment prospects for this group".

I think the critical takeaway for all readers of the JVR, and especially the APSE membership is this: How is it that we have become so knowledgeable in supported employment and VR techniques, yet this group of persons has been left so very far behind? I think there is a powerful message here to Congress, disability groups and business: We are wasting a major human resource and a major source of talent and we must set significant goals for change going into 2014-2020. Human dignity demands it.

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