Developmental Disability & Employment: A Social Work Priority

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Americans with developmental and other disabilities are often excluded from society due to the assumption that they cannot or do not wish to work. This paper examines the possibilities for and benefits of creating jobs for persons with developmental disabilities through the lenses of policy, law, evidence-based practice and social work ethics. While different perspectives on this issue exist, it is important to reframe our assumptions about the employment of people who have developmental disabilities, taking our cues from these individuals, rather than personal, professional, or societal notions. These notions, if they frame people as unable to participate in our culture, can undermine the many achievements that those with disabilities have fought for in law and public perception. Including people with developmental disabilities in the workplace is beneficial to these individuals and society in a variety of ways. This paper provides an overview of some excellent models of how to create space for people with developmental disabilities who wish to be employed in the workplace and outlines reasons why this type of economic inclusion is essential in order for these individuals to be included in American society. As specialists in understanding the gap between society and those who are typically rejected from it, social workers are well positioned to find creative solutions for this problem.

According to the United States Administration on Developmental Disabilities (ADD), developmental disabilities are "severe, life-long disabilities attributable to mental and/or physical impairments, manifested before age 22. Developmental disabilities result in substantial limitations in three or more areas of major life activities: capacity for independent living, economic self-sufficiency, learning, mobility, receptive and expressive language, self-care, and self-direction" (ADD, 2004, p. 1). There are approximately 4.5 million individuals with developmental disabilities in the United States. National rates of developmental disabilities, including Autism Spectrum Disorders, are thought to be rising. According to the Centers for Disease Control and Prevention (CDC), currently one in 150 children born will have autism as compared with one in every 222 in 2000 (CDC, 2007). People with developmental disabilities have an unemployment rate of 72 percent, in comparison with five percent of the population

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as a whole (United States Census Bureau, 2006; United States Department of Labor, 2008). As people of a nation that claims to allow citizens life, liberty and the pursuit of happiness, and as social workers who adhere to a code of ethics which espouses social justice, the dignity and worth of each person, and client self-determination, it is crucial that we work toward the inclusiveness of people who have developmental disabilities (National Association of Social Workers [NASW], 1999).

While pushing away that which may create cognitive dissonance and allow people who are not affected by developmental disabilities (DDs) to live more comfortable lives in the short-term, the relegation of people with DDs to special facilities excludes them from adequate and equal education, employment, transportation, recreation and other activities, harming us all (Whitehead & Hughey, 2004). The Administration on Developmental Disabilities (ADD) recently released a report entitled, "The American Dream Belongs to Everyone," which describes the purposes and implications of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (P.L. 106-402) and highlights the importance of the societal inclusion of developmentally disabled (DD) individuals (ADD, 2004). Details of this report, discussed later in this paper, demonstrate the steps that the United States government is taking to ensure the rights of people with DDs. Social workers might tend to agree that the "American Dream" should belong to everyone; however, programs for and treatment of people with DDs do not always reflect our code of ethics (NASW, 1999).

Developmental Disability: History and Legislation

Traditionally, people with disabilities have often been considered unable to contribute to society because they have been labeled "sick" or "dependent." Early public policies reflected this social construct of disability. Public benefits program requirements have tended to disenfranchise and disempower recipients by requiring that they fall below certain functional benchmarks in order to receive services (Whitehead & Hughey, 2004). Since the 1960s, the disability rights movement has helped individuals with disabilities re-label themselves as whole people and participants in society capable of making choices for themselves. This movement eventually led to government-funded sheltered workshops and vocational programs, set up to provide work experience for individuals with DDs (Kregal, Wehman, & Banks, 1989). In the 1980s, the use of sheltered workshops began to evoke wide criticism due to the degree in which they isolated people with DDs from mainstream society. In the late 1980s, supported employment

began to replace sheltered workshops as the generally accepted method of skill-building and employment for people with DDs (Bond et al., 2001). This shift toward supported employment fits appropriately in a society where the centrality of work is undeniable (Akabas & Kurzman, 2004).

The Americans with Disabilities Act of 1990 (ADA) was one important milestone in the effort to ensure that those with DDs are able to participate in the workforce (PL 101-336). Some see the ADA as an attack on the welfare state and an attempt to push people off of welfare rolls. They cite the possibility that individuals with disabilities are still extremely limited by the courts' stricter-than-intended interpretation as skepticism of ADA law. Judges sometimes decide that people with disabilities do not qualify for as many provisions as the law was originally intended to provide. Further, those who challenge the law feel that the ADA's enforceable accommodation standards (e.g., making a large company install a ramp for wheelchair access) may create negative employer reactions because they are averse to making the necessary and required accommodations (Bagenstos, 2004). While proponents of this view believe that improved social welfare services are a better answer to barriers than the ADA, they fail to recognize that the dominance of these services alone was the very system disability activists fought to change. The reality that people who have DDs may still be discriminated against despite ADA legislation should not stop DD individuals and their guardians from working toward a society that recognizes DD individuals' civil rights. TASH (formerly The Association for Persons with Severe Handicaps), an international association of people with disabilities, their family members, and advocates, has outlined a variety of lobbying and educational efforts designed to include people with DDs in the workplace, based on the belief that "no one with a disability should be forced to live, work, or learn in a segregated setting; that all individuals have the right to direct their own lives" (TASH, 2008).

The Social Security Administration offers special provisions that ensure that people with disabilities can work and continue to receive Social Security Disability Insurance (SSDI). These provisions, called work incentives, include provisions for individuals to set aside money, resources, and expenses that are excluded from earned income calculations (Fichthorn & Scott-Gilmore, 2005). The ADA is focused on ensuring that those with disabilities are able to enjoy an equal opportunity to participate in society—including the culturally-valued realm of employment. The Equal Opportunities Employment Commission seeks to eliminate barriers to employment for individuals with DDs by providing de-incentives in the form of fines to those employers who discriminate (Equal

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Employment Opportunity Commission, 2008). Unfortunately, there is a growing body of evidence that people with developmental disabilities are discriminated against at higher levels than people with physical disabilities (Gouvier, Mayville, & Sytsma-Jordan, 2003). Overall, the ADA is an important progression within our society that furthers the cause of people who have DDs and wish to work. Importantly, the ADA furthers this cause without reducing (or failing to advocate for) the much-needed benefits of those individuals who may not wish to or who are not able to work.

This paper proposes that gainful employment is an excellent way to ensure that DD individuals are given the self-determination valued by society. While some individuals are treated for their developmental disabilities during childhood, others carry their developmental disabilities into adulthood. As their parents age, and less-than-adequate caretaking facilities remain the norm, these individuals' life options are severely limited (Pruncho, 2003). As the ADD (2004) report notes, "locating and/or maintaining reliable and stimulating employment is one of the most important steps individuals can take towards personal and financial independence" (p.3). Not only does this employment benefit society, it also allows fellow citizens the personal choice to decide what degree of independence they wish to have. While the ADA champions the right of DD individuals to work, which is significant for their inclusion in society, the provision of this right does not necessarily create the opportunity for work.

The Developmental Disabilities Assistance and Bill of Rights Act of 2000 proposes 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…" (Title 1 P.L. 106-402) (ADD, 2004, p.2). Other important legislation that aids people with developmental disabilities include the Americans with Disabilities Act of 1990 (P.L. 101-336), the Social Security Act (P.L. 74-271), the Rehabilitation Act (P. L. 93-112), and the Individuals with Disabilities Education Act (IDEA) (P. L. 101-476), each of which addresses one or more of the forms of discrimination faced by individuals with disabilities (ADD, 2004). These policies put into place important supports for people with DDs: the ADA ensures appropriate workplace accommodations and outlines penalties for discriminatory practices; the Social Security Act provides funds for living and medical care; the Rehabilitation Act attends to vocational and rehabilitation services; and the Individuals with Disabilities Education Act addresses the educational needs of children with disabilities from birth to age 21. Another recent piece of legislation

that aims to benefit people with developmental disabilities is the New Freedom Initiative, launched by President George W. Bush on February 1, 2001. The goal of this initiative is to promote full access to community life for people with DDs through the collaboration of federal agencies in removing barriers to independent living (ADD, 2004). Together, these pieces of legislation seek to empower individuals with disabilities to advocate for themselves, build social capital and increase support and choice within the service organizations that affect them and society as a whole.

The Administration on Developmental Disabilities is responsible for the implementation and administration of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act). Federal funding from the ADD allows for programs, including State Councils on Developmental Disabilities (SCDD), to pursue systems changes in service or support availability. Further, the legislation makes it possible for Protection and Advocacy (P&A) systems to protect the legal and human rights of individuals with disabilities and for University Centers for Excellence in Developmental Disabilities (UCEDDs) to provide interdisciplinary pre-service preparation and disseminate research findings. Projects of National Significance (PNS), also made possible by this legislation, address areas of emerging concern through discretionary funds (ADD, 2007). This funding, along with private donations and corporate and foundation grants, has allowed for the creation of a wide range of programs for individuals with DDs. However, the number of people with DDs that states serve through employment programs remains low as compared to beneficiaries of programs such as education and quality assurance that are also designated for people with DDs (ADD, 2006).

While the existing programs provide important services to people with developmental disabilities, the talk of empowerment in the legislation and human service literature is inconsistent with the fact that there are not more programs devoted to employment. Employment can lead to empowerment through skill and creativity-building, earning wages, having control over one's money and contributing to the economy and to the social work environment. Despite the fact that 14 percent of people with disabilities who are seeking work are unemployed compared with five percent of the population as a whole, the provision of employment programs for people with disabilities is insufficient (CDC, 2007). While people with DDs have benefited from the programs provided by the above mentioned legislation, recent research has shown that these have not been enough to ensure that individuals with DDs are participating in the American workplace through integrated jobs (Metzel, Boeltzig, Butterworth, Sullivan-Sulewski, &

Scott-Gilmore, 2007). In other words, while legislation and non-employment programs are plentiful, real jobs are few.

In order for individuals with developmental disabilities to truly be included in society and reap the benefits that work can offer, this paper proposes a shift toward integrated employment in federally-funded projects. While the reality is that some persons with developmental disabilities may need a great deal of assistance or even full-time care, the majority of DD individuals is able to perform some work. Unfortunately, studies have shown that individuals with DDs in program care settings exhibit a significant amount of "learned helplessness" in language use, adaptation and behavior. This raises concerns regarding health, physical safety and individual development, because individuals with DDs learn to accept substandard living conditions and lower expectations regarding their potential (Reynolds & Miller, 1985; Domingo, Barrow, & Amato, 1998; Janssen, Schuengel, & Stolk, 2005). While caregivers and those who shape programs tend to see the developmentally disabled as having little ability to develop without a sheltered environment, studies have shown that even severely autistic individuals have personal preferences for certain tasks in the workplace (e.g. vacuuming vs. dusting) (Lattimore, Parsons, & Reid, 2002). This ability illustrates that even those individuals typically considered lowest functioning can acquire skills to make choices, learn, and interact in a social or work setting. Is it really these individuals' disabilities that keep them from productive employment, or it is society's view that they have no potential to contribute that isolates DD individuals and consigns them to lives of segregated stagnation outside the traditional bounds of our work-centered society?

Inclusive Education and Inclusive Employment

In recent years, following a national debate about educational inclusiveness, the movement for Inclusive Education for people with developmental and intellectual disabilities in our nation's classrooms has experienced much success. This achievement is evidenced in the surge of opportunities for children with and without disabilities to be educated together, under the clause of IDEA legislation that requires free and appropriate education in the least restrictive environment (Klierwer, 1998). Klierwer (1998) explains:

> "Segregated education separates people from their own culture.
> It denies them the right to participate in the complex and ever-
> changing realities that constitute regular lives. Segregation does
> not lead to community participation; it leads to the need for fur-

ther restrictive placements. On the other hand, inclusion is about full membership; and in that active participation, the form and shape of the community itself is changed as traditionally banished people alter the very appearance of who and what constitute valued and effective membership" (p. 318).

The concept of inclusive education can also be extended to incorporate inclusive employment. It is important to continue to address the negative impacts of separation from culture and membership in society as people with developmental disabilities complete their educational programs. Is it not cruel to educate people in an integrated manner only to send them out into a cultural reality where they find no place to belong due to the lack of employment options? Laying the groundwork for inclusive employment may be difficult in a culture so permeated by capitalistic ideals. Advocates and scholars have laid a solid foundation of research and program ideas in the past decade; yet proposing practical, creative and effective programs that serve both society and individuals remains a contemporary challenge for social workers.

Building toward Employment: Skills and Preparation

Wehman (2006) has stressed that the developmentally disabled population is heterogeneous and that each group of people with specific developmental disabilities has unique strengths and barriers. This reality highlights the importance of understanding each type of developmental disability while taking care to focus on the person, not solely on the disability. To that end, Wehmeyer, Garner, Yeager, and Lawrence (2006) have identified a multi-stage, multi-component model to promote DD student involvement in transition planning and implementation. This model incorporates social interaction, community inclusion, outcome measurements, skill-building and family/caretaker involvement to help ensure the participation and perspectives of people with developmental disabilities.

In Stage One, high-quality supports enable students to establish short- and long-term goals based on their own preferences, abilities and interests. Students were involved in "Whose Future is it Anyway?", a curriculum designed to increase DD students' self-awareness and build problem-solving, decision-making, goal-setting and small group communication skills (Wehmeyer & Kelchner, 1995). The Self-Determined Learning Model of Instruction allows students to become self-regulated problem-solvers and to self-direct transitional goal-setting, action planning and program implementation (Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000).

Stage Two involves convening a student-directed, person-centered planning meeting that incorporates stakeholders in the learning process to help students refine goals (such as, "I will make a budget based on my paycheck and learn to use my budget") and provides support for the second phase of the Self-Determined Learning Model of Instruction. In the final stage of the model, the student, along with supports identified in the second stage, implements the plan, monitors his or her own progress, and evaluates his or her own success, making revisions to the goal or the plan as desired (such as, "I will ask my vocational counselor for help if I cannot understand my paycheck").

This curriculum provides an excellent model of employment preparation for people with disabilities. With proper planning, this model can foster many of the skills needed in an integrated workplace, including group communication, goal-setting, action-planning, self-determination and self-awareness. In fact, after the intervention, students demonstrated significant increases in autonomy and independent living skills and lower levels of learned helplessness (Wehmeyer et al., 2006). It is imperative that students learn these skills as they transition to the workplace because they are important for self-determination, which has been sought by DD individuals and is crucial for transitioning to supported employment. Additionally, individuals with DD typically work with a vocational counselor, whose job it is to assist them in implementing their plans as well as in gaining and maintaining employment (Palmer & Wehmeyer, 1998; Wehman, 2006). It is these vocational counselors who help students transition to employment in an inclusive setting.

Inclusive Employment

Several researchers have outlined approaches to integrated employment programs that offer positive outcomes. By contrast, sheltered employment programs have drawn criticisms due to lack of staff knowledge about job and personal development, low expectations, and low integration with communities (Rusch & Hughes, 1989). Rusch & Hughes (1989) describe several positive models for job placement and transition: (a) the individual placement model, in which an individual is placed in a workplace with the continuing support of a vocational counselor; (b) the clustered placement model, in which a group of individuals works in close proximity within a workplace, often performing the same task; (c) the mobile crew model, in which a group of fewer than eight employees provide contract services (e.g., grounds work) in the community; and

(d) the entrepreneurial model, in which a group of fewer than eight employ-ees provide a product or service (e.g., electronics assembly) to a manufacturing company. The group models (b, c, and d) are considered appropriate only for extremely low-functioning individuals because mean hourly wages and levels of integration, two important positive outcomes, are greater for workers who have been individually placed (Kregel, Wehman, & Banks, 1989).

Wehman (2006) outlines job-searching steps for DD individuals and rec-ommends job coaches that can further integration. Researching the job market, working with the potential employee to identify and build a network of business contacts, presenting to the employer in a positive manner that showcases the potential employee while answering any questions or concerns, and educating the employer on relevant legislation are important steps toward obtaining em-ployment. Steps that will formalize and finalize employment include ensuring that job development activities are being implemented effectively and efficiently, conducting a meeting with the employer and employee in which expectations are presented and choices are given, ensuring that the employee and employer understand the terms of the contract, and (later) asking the employee if she or he would like to take the job.

Another important quality for job searchers to consider about potential places of employment for DD individuals is the degree to which workplace inclusion is possible. The number of opportunities for physical and social in-tegration, whether all employees (including DD workers) participate in these opportunities, and whether the workers are satisfied with the job setting and the opportunities it offers should all be evaluated. Particular value should be placed on whether the DD workers are comfortable with other employees, included in general workplace activities, and provided with opportunities to develop new skills and learn new tasks. Each of these aspects of a work environment must be monitored during the follow-up process, in which a vocational counselor contin-ues to work with and support the individual who has been placed for employment (Wehman, 2003).

The vocational counselor must indicate to the employer the need to return for intermittent Job Analysis appointments in which the counselor evaluates the fit between the employee's skills and the job he or she is performing (Wehman, 2006). "Systematic and ongoing assessment of the job setting and the worker is critical if maximum integration is to be achieved and maintained" (Wehman, 2003, p.139). This is the case because individuals with DDs, more so than non-DD individuals, can fall behind quickly if they are not receiving an appropriate degree of support in the workplace. The counselor should constantly be looking

to explore the need for accommodation, information about the company and its services, opportunities for development and promotion, how technically and socially inclusive the work environment is, and how to proactively and creatively provide any other needed support. Menchetti and Garcia (2003) emphasize supportive training for employees, employers and service providers, collaborative problem solving, and continuous process improvement as crucial components of job stabilization. Conflict resolution skills, positive interviewing and knowledge of the indicators of depression and anxiety to ensure an employee's wellbeing throughout his or her employment would also be helpful in providing individuals with DDs the support they may need to thrive in an inclusive employment setting.

The Cost-Effectiveness of Supported Employment

Not only do many individuals with DDs, their guardians, and scholars prefer the shift toward inclusive employment, it is also cost-effective for these individuals and for society (Kregel, Wehman, & Banks, 1989; Cimera, 1998). Including DD individuals in the workplace can lead to increased understanding of the needs of and appropriate responses to a wide variety of consumers, and therefore increase company sales or productivity (Mor Barak, 2000). Cimera (1998) provides an extensive literature review and economic analysis, which examines the cost-efficiency of supported employment for individuals with developmental disabilities. Cost-benefit ratios were used to measure cost-efficiency from the perspective of the worker, the tax-payer and society. Costs and benefits included supported employee operating costs, alternative program operating costs, gross wages, forgone wages, fringe benefits, taxes withheld, interest on taxes withheld, taxes refunded, reduced subsidies and targeted job-tax-credits. Societal costs were supported employee operating costs, forgone wages, and targeted job tax credits. Societal benefits were alternative program operating costs and gross wages. Cimera (1998) concluded that, "supported employment programs are a good [cost-effective] investment for workers, taxpayers, and society in general. Even more important, results showed that regardless of the severity and number of disabilities, supported employment is cost-effective for all individuals." (p. 89). The above research provides several reasons why employment in a real work setting is a cost-effective option for everyone involved.

A Social Work Opportunity

With so much groundwork for supported employment laid by individuals with developmental disabilities, advocates, and scholars, there remains an excellent prospect for social workers to bind the policies with the curriculum already set forth and create opportunities for work for the developmentally disabled in our society. There remains a deep need for workers to provide the actual services necessary to take action on the resources provided. At the level of service provision, social workers can work collaboratively with people who have DDs (and their guardians) to create linkages with prospective employers and individually tailor supportive services appropriate to their needs (Parish & Lutwick, 2005). Social workers can work as liaisons between various parties in the employment process, advocating for those DD individuals who wish to be employed in the workplace and involved in the community (Akabas & Kurzman, 2004). By doing so, social workers are answering the call of the NASW policy to work with individuals with disabilities and their families to provide services that are respectful, appropriate and directed by individuals with disabilities (NASW, 2000).

Conclusion

The above-mentioned curriculum and programs designed for inclusive employment outline an effective response that social workers can use to address the lack of viable employment opportunities for individuals with DDs. The failure for real programmatic shift toward integrated employment despite the pro-autonomy language of current legislation, the general attitudes (conscious or unconscious) of caregivers and the American public as exhibited in the history of our treatment of DD people, as well as the learned helplessness and latent potential of these individuals, reveal a need for stronger emphasis on well-planned, self-determined employment options. These options must be provided with careful preparation and training, supportive transition and detailed follow-up. As experts in interpersonal relationships, navigating the space between social systems and people's lives and the great degree of impact legislation has on individuals, social workers are well-positioned to confront the lack of inclusiveness for citizens with DDs who desire to participate in our society through gainful employment.

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