

Health and Wellness Research Study: Access to Health Care

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#### Introduction

The Office of Disability Employment Policy (ODEP) within the U.S. Department of Labor (DOL) uses research, policy analysis, and the development and distribution of knowledge transfer products to address employment challenges facing people with disabilities. ODEP provides national leadership on disability employment policy by developing and encouraging the use of evidence-based disability employment policies and practices, building collaborative partnerships, and delivering authoritative and credible data regarding employment of people with disabilities. This review of research and policy on access to health care for people with disabilities aims to formulate recommendations that assist ODEP in developing guidelines for future disability employment and health care research. <sup>1</sup>

Section 1.0 begins with an overview of system- and treatment-level factors that appear to have the most significant impact on access to affordable health care for people with disabilities. Section 2.0 presents a discussion of labor market segmentation and the influence of socioeconomic status and labor market position on health insurance coverage availability. Section 3.0 provides an employment profile of people with disabilities, while Section 4.0 compares the features and scope of Medicaid and Medicare, discusses the work disincentives posed by these two programs, and presents public policy initiatives implemented to promote the return to work of people with disabilities. In Section 5.0, we discuss promising practices in health-care financing, public subsidized health-care programs, and the efforts of three large businesses to make comprehensive health insurance coverage more affordable for their employees. In this section, we also provide information on collaborative initiatives among employers, home and community-based social service providers, and primary care organizations that improve access to health insurance coverage for marginalized groups. We conclude in Section 6.0 with a summary of findings and recommendations for future research on employment and access to health care for people with disabilities.

<sup>1</sup> This document is a required deliverable under ODEP Task Order DOLU089428186 (Health and Wellness Study).

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#### **Table 1. Research Questions**

#### A. DISINCENTIVES TO WORK

- 1. What are the health care access disincentives that affect the recruitment and retention of workers with disabilities?
  - 1.1 What programs have been put in place to address these disincentives?
  - 1.2 What gaps remain in existing programs and policies that disincentive transitions to work and reemployment for people with disabilities?
- 2. What kinds of programs, policies and support services prolong labor force participation or delay disability program participation among workers with disabilities?
  - 2.1 What are the attitudes of people with disabilities in the workforce regarding the kinds of programs that would support or prolong their labor force participation?
  - 2.2 What research has been conducted on health care access that prolongs labor force participation?
  - 2.3 What are "forward-thinking corporations" doing to address barriers to health care for employees with disabilities?
    - 2.3.1 How effective are these programs in terms of their impact on health care costs and reductions in employment interruptions among people with disabilities?
- 3. What types of interventions could be undertaken earlier in the disability onset process to prevent/delay labor force withdrawal and how might such interventions be financed?
  - 3.1 To what extent does the type and severity of a disability prevent/delay labor force withdrawal?
  - 3.2 How should interventions be customized to support different levels of disability severity?
  - 3.3 What are the cost differences for interventions that may prevent/delay labor force withdrawal by type and severity of disability?
- 4. What measures could be used to assess impact?

#### **B. EMPLOYER-BASED GROUP COVERAGE**

- 5. How can access to adequate health insurance be assured for people with potentially disabling conditions who do not qualify for employer-based group coverage so that they can remain in the workforce?
  - 5.1 What health care options exist for individuals with potentially disabling conditions who do not qualify for employer-based group coverage so that they can remain in the workforce?
  - 5.2 What are/should be the options for individuals with potentially disabling conditions who do not qualify for employer-based group coverage so that they can remain in the workforce?
  - 5.3 What are the cost-to-benefits of these programs?

#### **C. BEST PRACTICES**

- 6. How will employers utilize best practices and lessons learned to develop and enhance employee access to health care?
  - 6.1 What promising or best practices are currently being used by employers to develop and enhance access to health care for employees with disabilities?

#### D. COLLABORATION

- 7. What can be done to encourage the most effective working relationships between employers, home and community-based social service providers and primary care organizations?
  - 7.1 What existing employer/health care/provider networks have had success in developing effective working relationships?
  - 7.2 What are the characteristics of these programs?
  - 7.3 What are the measures which determine value added employment and health service partnership?

This research review emphasizes the importance of the labor market's job allocation process, the disincentives inherent in the public health care subsidy programs in the United States, and the concentration of market share within the health insurance industry as key system-level factors that limit access to health care for people with disabilities. In addition, treatment-level variables, such as disability type and severity and myriad psychological and sociological factors, are important secondary factors that contribute to the difficulties many people with disabilities experience in the mainstream labor market.

The authors view access to health care primarily as a function of labor market position in that people with disabilities with primary labor market credentials (i.e., skills and education to be hired for higher-grade, higher-status, and better-paid jobs) are more likely to have access to health care than those in secondary labor market jobs (i.e., jobs that require few skills, little training with low wages and few benefits). Thus, the latter group has a greater incentive to rely on public health subsidized programs rather than return to work. Based on work by Foreman, Murphy, & Swerissen, 2006; Niemeyer, 2000; and Vroom, 1994, we created a bio-psycho-social model that illustrates the interaction of system- and treatment-level factors on the likelihood of workers with disabilities returning to work when they are more likely to have access to health insurance coverage (Schur, Kruse, & Blanck, 2005; Vroom, 1994; Waddell & Burton, 2000).

In Boxes 1, 2, and 5, the model presents treatment-level variables, including the availability of treatment and workplace disability management procedures, the human capital characteristics of workers with disabilities, existing insurance coverage and workers' expectations that they will return to work. In Box 5, type and severity of disabilities are shown to influence the return-to-work expectations of people with disabilities. These factors are influenced by human capital characteristics and the workplace environment. Boxes 3 and 4 present system-level variables that interact with treatment-level variables. For example, family support and job characteristics prior to the onset of the disability play important roles in the employees' expectations for regaining stable employment. The bio-psycho-social model offers a comprehensive view of the return-to-work process, with access to affordable health insurance coverage playing a central role. However, existing research in this area has not adequately controlled for the factors included in the model and, therefore, may understate the needs of people with disabilities.

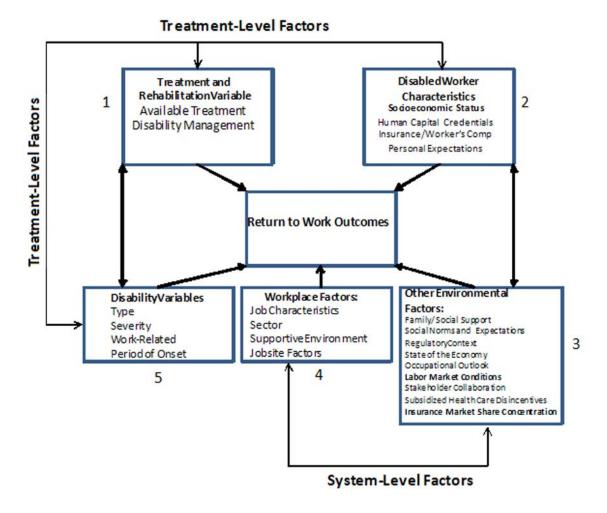


Figure 1: Bio-Psycho-Social Model

In the following section, we provide a more detailed explanation of system- and treatment-level factors that inhibit access to health care for people with disabilities.

# 1.0 Key Barriers to Health Care Access for People with Disabilities

The American health care system is challenged by the convergence of federal and state policies, a free market economy, and the economic complexities of the labor market, all of which play a role in limiting access to health care for people with disabilities. In the following sections, we provide explanations of how socioeconomic status, work disincentives, and health insurance market consolidation affect the health care system and unnecessarily limit access to health care. In subsequent sections of this review, we revisit these topics in the context of subsidized health care programs and their impact on workers with disabling conditions.<sup>2</sup>

#### 1.1 Socioeconomic Status and Labor Market Position

Access to health care is *intrinsically* linked to socioeconomic status and labor market position. People with disabilities are disproportionately poor and have low rates of economic, occupational, and/or social mobility (Hertz, 2006; Schartz, Hendricks, & Blanck, 2006).<sup>3</sup> In basic terms, less than one quarter (22.5%) of people with disabilities who are attached to the primary labor market are likely to have access to, and be able to afford, comprehensive employer-based health insurance coverage. Those employed in the secondary labor market are even less likely to be insured. In the event that a low-wage worker with a disability is employed in the subordinate-primary labor market (i.e., a semi-skilled job that supports skilled workers), where employer-based health insurance coverage is often available, that worker is unlikely to be able to afford the premium, deductible, co-pay, and coinsurance fees without the use of public health care subsidies.

Due to limitations in opportunities for human capital development, the existence of workplace prejudice and discrimination and disabling functional impairments (Collela, 2001; Louvet, 2007; Schur et al., 2005; Wooten & James, 2005), people with disabilities have a much higher rate of poverty than the general working-age population (Burton Blatt Institute [BBI], in press; U.S. Census Bureau, 2007). As a result, they are disproportionately allocated to low-wage (secondary) labor market positions, where only one in five (20 percent) workers with disabilities have affordable employer-based health insurance coverage (Henry J. Kaiser Family Foundation, 2003). This situation perpetuates occupational inequality and a bifurcated (segmented) labor market, where segregation is based on the exclusion of marginalized groups from primary labor market jobs (Grusky & Szelenyi, 2006). This environment diminishes the likelihood that people with disabilities have access to non-subsidized health insurance coverage.

Research on economic mobility indicates that socioeconomic status, mediated by disability severity, is a key predictor in determining access to health care for people with disabilities. Socioeconomic status has been described as "the ignored determinant of the nation's health" (Minkler, Fuller-Thomson, & Guralnik, 2006), despite the considerable research showing that "declines in the rate of functional

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<sup>&</sup>lt;sup>2</sup> The current recession in the United States has created additional hardship for secondary labor market workers, where the majority of people with disabilities are employed. The administration's stimulus package may provide some temporary benefit to people with disabilities through subsidies that extend unemployment benefits; increase the availability of food stamp benefits; and provide a one-time stipend of \$250 for Social Security recipients, people on Social Security Disability Insurance (SSDI) and veterans with disabilities. The package also includes insurance premium subsidies for the unemployed under the COBRA program and financial support for state Medicaid programs and modernization of health information technologies as well as subsidies for special education programs at the school district level, early childhood education through the Head Start program, small tax credits for workers, and additional support for the Pell Grant program.

<sup>&</sup>lt;sup>3</sup> The marginal effect on overall earnings for people with disabilities is -23% relative to workers without disabilities, and another -17% decline in earnings for minorities with disabilities, relative to their non-minority counterparts (Santiago, & Muschkin, 1996).

<sup>&</sup>lt;sup>4</sup> For example, "organizational routines," including harassment, an unwillingness to provide reasonable accommodations, lack of infrastructure to support employees with disabilities and stereotypes negatively affect the quality of workers with disabilities' work environment.

limitation" are associated with decreases in income and level of education (Minkler et al., 2006; Mwachofi & Broyles, 2008). As an indicator of quality of life, socioeconomic status is central to the short-term transitions and long-term trajectories that people with disabilities encounter throughout the life-course (Blanck, Adya, Myhill, Samant, & Chen, 2007; Manton, 1988; Taylor & Lynch, 2004).

#### 1.2 Work Disincentives

The historical lack of remunerative work incentives in public health care subsidy programs, such as Social Security Disability Insurance (SSDI), Medicare, and Medicaid, is another factor that limits access to health care for people with disabilities. People with disabilities who return to work must consider the economic implications of their decisions as well as their ability to secure employment in the primary labor market rather than the secondary labor market, where affordable health insurance coverage is less likely to be available. People with disabilities who lack the training and experience needed to obtain a position in the primary labor market have a strong disincentive to remain unemployed and eligible for subsidized public health insurance.

Public health care subsidy programs require the removal of benefits after a brief trial-period of employment, thus creating a disincentive for people with disabilities to return to work. It has been alleged that some SSDI beneficiaries abuse the public health care subsidy system in order to continue to receive SSDI benefits, regardless of their disability status. One statistic that is used to substantiate this claim is the SSDI voluntary exit rate, which is estimated to be about 1 in 500 (.20%) recipients per year (U.S. General Accounting Office [GAO], 1997). While this rate is surprisingly low, it does not necessarily indicate abuse of SSDI. Rather, it may signal a concern on the part of people with disabilities that reentering the labor market will result in a dramatic reduction in affordable health insurance coverage (Stapleton & Burkhauser, 2003). 5,6,7

The Social Security Administration's (SSA) largest effort to remove the disincentive to work is the Ticket to Work (TTW) program, which was implemented in 1999 (Blanck et al., 2007). TTW offers SSDI beneficiaries a trial work period of up to nine months, 7.75 years of ongoing Medicare eligibility following return to work, and three years of automatic benefit reinstatement if earnings fall below 200 percent of the Federal Poverty Level (FPL). To date, however, the program has not produced significant improvements in participant earnings or labor market attachment (Auter & Duggan, 2003).

TTW is a performance-based program that may create a disincentive to serve people in the following so-called Adequacy of Incentives (AOI) groups: (1) beneficiaries who require ongoing support and services to work; (2) beneficiaries who require high-cost accommodations to work; (3) beneficiaries who work but earn a subminimum wage; and (4) beneficiaries who work and receive partial cash benefits (Gallagher, 2004). Employment networks (groups of employment development and service agencies) are compensated when participants achieve certain employment-related outcomes such as stable employment and increases in earnings. An SSA contractor helps employment networks access capitalization education, which is the training provided to help them identify and obtain alternative funding. In addition, employment networks are not required to serve all ticket holders, as they determine which services they will offer and the types of ticket holders they are equipped to serve. They

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<sup>&</sup>lt;sup>5</sup> Research on abuse of the SSDI program has uncovered only a few high-level court cases, occasional agency negligence, and questionable decisions made by Social Security Administration workers involved in the five-step eligibility process (Taylor, 2004). But no rampant abuse by people with disabilities is evident.

<sup>&</sup>lt;sup>6</sup> Also important is the Social Security Administration's estimate that without SSDI, the poverty rate for families with a worker with a disability would increase from 18.5 percent to 55.0 percent (Social Security Administration, 2008).

<sup>&</sup>lt;sup>7</sup> A full eight years after the implementation of welfare reform, Bavier (2001) reports a 60 percent increase in the number of single mothers in the bottom fifth of the income distribution, the majority of whom are both unemployed and uninsured.

also may terminate agreements with ticket holders by informing the SSA contractor responsible for TTW administration (Stapleton et al., 2008).<sup>8</sup>

According to TTW researchers, "Although the findings on TTW participation indicate that providers are equally willing to *accept* Tickets from AOI and non-AOI beneficiaries, overall, we found some evidence for providers' concern about their ability to serve AOI beneficiaries adequately or to induce them to participate in TTW. This observation applies especially to those in Groups 1 and 2 who might require more intensive or long-term support if they are to secure employment. Their participation rates are relatively low, and they are more likely than others to have assigned their Ticket to a vocational rehabilitation agency under the traditional payment system. Although these groups had low involuntary nonparticipation rates, those in the groups whom we interviewed reported greater unmet service needs than those in other AOI groups" (Stapleton et al., 2008).

TTW researchers report that for employment networks to be profitable, they must generate an average of 10 to 22 payments for every participant, but less than 15 percent of all participants achieved outcomes that led to payments to employment networks and even these participants generated only nine payments during the first two years after enrolling in the program (Stapleton et al., 2008). Overall, TTW has shown only moderate impact on participant outcomes: "Across all age program groups, the estimates for both earnings and benefits paid are negative and significant....As impacts on earnings are expected to be positive and negative impacts on benefits logically follow only from positive impacts on earnings, the interpretation of these estimates as impacts is problematic" (Stapleton et al., 2008).

Recent qualitative research on factors that influence decisions among workers with disabilities to return to work describe a long-term process that requires different kinds of treatment interventions throughout the post-injury rehabilitation phase (Franche & Krause, 2002). Several researchers have used developmental theories to explain the phases of rehabilitation and the return-to-work process. Young et al. (2005) proposed a developmental model that includes a "cycle of phases" in the overall process from work injury to substantial gainful activity (SGA) and taxonomy of return-to-work actions for each phase. For example, the initial phase in this model is an *off-work* phase during which at least partial physical recovery is required before work re-entry can be attempted. At this phase a worker with a disability undergoes key return-to-work tasks that would include an assessment of work abilities, work intentions, identification of employment goals, and a strategic plan to achieve goals. The return-to-work tasks in the next phase (work re-entry) are likely to be different and focus on facilitating the match between available jobs and technical abilities. Increasingly, there is evidence that treatment of workers with disabilities must consider the type of disability and its severity, as well as the phase of injury and period of disability onset (Meijer, Sluiter, & Frings-Dresen, 2005; Ozguler, Loisel, Boureau, & Leclerc, 2004).

There is evidence that health care and therapeutic counseling motivate workers with disabilities to resume normal activities and lead to better outcomes than medical treatment alone. Research also has shown that communication, cooperation, and establishing a shared set of goals among the injured worker, health care providers, supervisors, and management is critical for improvement in both clinical and occupational outcomes (Franche & Krause, 2002). Finally, there is evidence that psychosocial factors such as workers' fears and beliefs about their conditions, the impact of re-entry to the workplace on their health, and the promotion of self-responsibility and self-care are critical domains that need to be included in these rehabilitation approaches (Staal, Rainville, Fritz, Mechelen, & Pransky, 2005).

There is growing consensus that while attending to the physical/medical aspects of workers with disabilities is important, much of the variability in return-to-work outcomes is accounted for by what

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<sup>&</sup>lt;sup>8</sup> For example, TTW researchers report that participant characteristics such as age, education, and presence of children living in the home play a greater role than the individual's disability in explaining variability in participation rates.

takes place at the workplace (Franche et al., 2005). For example, there is increasing evidence that workplace-based interventions are more effective than those provided outside the workplace (Anema et al., 2004). These authors conclude that a positive and open relationship between the health care provider and workplace, and the availability of work accommodations, leads to significant reductions in the length of the return-to-work process. In addition, direct contact between the worker and the workplace and the presence of a return-to-work coordinator may further reduce the time off work.

Some of the qualitative research on barriers to employment for people with disabilities focuses on the negative attitudes of employers and coworkers, stereotypes of employees with disabilities that are unfairly critical of their work productivity, the cost of workplace accommodations, and turnover and absenteeism. Hernandez et al. (2008), in a study of employer and coworker attitudes, found that employers frequently use negative stereotypes for workers with disabilities even though it "has become socially appropriate for employers to espouse positive global attitudes toward" people with disabilities in public. In Hernandez, Keys, and Balcazar's (2000) review of 19 studies, eight reported positive employer attitudes towards hiring workers with disabilities, while 11 revealed negative attitudes and consistent use of stereotypes to characterize and marginalize workers with disabilities. Several studies on employment barriers used multiple frame designs in which surveys and interviews were conducted simultaneously to collect information from employers, employees, consumers, and workers with disabilities, allowing for matrix comparisons identifying areas of agreement and disagreement, and the strength of correlations among and between each respondent group.

Schur et al. (2005) found that workers without disabilities often resent workers with disabilities' workplace accommodations and respond with negative stereotyping and prejudice, while Collela (2001) reported that negative attitudes occasionally influence employers to restrict the use of accommodations for employees with disabilities to maintain a copacetic work environment. Collela's (2001) findings are corroborated by Schur et al. (2005), who found that employees without disabilities are likely to perceive workplace accommodations as being unfair if the accommodations are thought to make the accommodated person's work easier, make the job harder for another person without a disability, an unwarranted reward or perk, and/or an unnecessary use of scarce resources that causes another worker to lose competitive rewards. Yet, the resources associated with the most common workplace accommodations, including extra attention by a supervisor or co-worker, flexible hours, and job coaching, are minimal (Olson, Cioffi, Yovanoff, & Mank, 2001).

Freedman and Fekso (1996) reported that stigma and discrimination by employers and professional employees were the most frequently reported barriers to long-term employment, in addition to discrimination with regard to task allocation policies, promotions, and job responsibilities. Wooten and James (2005) cited "discriminatory organizational routines," including harassment, an unwillingness to provide reasonable accommodations, lack of infrastructure to support employees with disabilities, and negative stereotypes as barriers to long-term employment. Discrimination at the job interview phase also has been identified. More negative perceptions of job candidates with disabilities than job candidates without disabilities among potential employers were reported in some studies (Bell & Klein, 2001; Gouvier, Lees-Haley, & Hammer, 2003; Scherbaum, Scherbaum, & Popovich, 2003), and Louvet (2007) found that applicants with disabilities are judged more negatively when they apply for positions that involve face-to-face contact with customers.

Crook, Moldofsky, and Shannon (1998) reported that after controlling for sex and age, psychological distress, and functional disability, the return-to-work rate for workers who were provided with modified jobs was two times higher than that for those with no such accommodation in employment. Krause, Frank, Dasinger, Sullivan, and Sinclair (2001) researched employment after injury for people who had suffered traumatic spinal cord injury and found early return to work both for the first post-injury job and

the first full-time post-injury job was less likely when the person was returning to their pre-injury job. Stressful work (Feuerstein, Berkowitz, Haufler, Lopez, & Huang, 2001) and low job satisfaction (Fayad et al., 2004) have also been associated with low return-to-work rates among people with disabilities. While there is general consensus that demographic and psychosocial factors are important considerations in predicting return-to-work outcomes, opinions regarding the degree to which they contribute vary. Brown et al. (1996) found that by combining cognitive and demographic variables, a logistic regression model was able to account for less than 30 percent of the variance in return-to-work outcomes. Schade, Main, Hora, and Boos (1999) found that in back-injured patients, outcomes were not affected by clinical factors, but solely by psychological factors (e.g., depression) and psychological aspects of work, such as job stress.

Quantitative studies predict the time it takes a person with a disability to return to work by incorporating multiple covariates in regression models. For example, Pluta and Accordino (2006) conducted a study of private sector, primary labor market workers with psychiatric disability claims who returned to work (N = 300) and compared the speed of return to work using a combination of demographic and vocational variables. The authors used hierarchical linear modeling (HLM) to explain variation in the dependent variable (number of days on claim) at multiple levels. Pluta et al. (2006) reported that the number of months in a given occupation is a significant predictor of return to work. The research found that for every one-unit increase of occupational experience, participants had an average decrease of 0.94 days out of work, while for every one-unit increase in a participant's age at return to work, the authors reported an average increase of 10.83 days out of work. It is important to mention that the factors that are typically predictive of return to work among low-income SSDI beneficiaries may not be the same for middle-class workers. For example, Anthony (1994) found that gender, age, and marital status were predictive of return to work among SSDI beneficiaries, whereas they were not predictive of the private sector dataset used by Pluta et al. (2006), indicating that socioeconomic status may have an interaction effect on the likelihood of returning to work for people with disabilities (Haring, Stock, & Okun, 1984).

Much of the quantitative return-to-work research indicates that the problem of access to health care is related to the period of onset of a disability. For example, using the data from the Health and Retirement Survey, Crimmins and Hayward (2004) explored the association between job type and disability among men and women aged 51-62. The authors estimated the onset of disability and its relationship to the probability of respondents working at baseline and a follow-up period. Results from a bivariate logistic regression analysis indicated that for men, employment after the onset of disability is associated with job stress and lack of job control, while for women, factors such as social support, job fulfillment, and quality of life are associated with reemployment after disability onset. In a similar study, Oi (1992) found that when controlling for age, reported health status is the most powerful determinant of labor market participation, while age was a significant predictor of the likelihood of a worker with disabilities returning to work, as workers 55 years of age or older were less likely to return to work compared with younger workers with disabilities.

Loprest and Maag (2003) studied the impact of reduced investment in human capital (education) for a cohort of people age 22 to 35 and a cohort of people age 44 to 54. Using data from the 1994 and 1995 National Health Interview Survey Disability Supplement, Loprest and Maag (2003) found that people with early onset of a disability had a lower probability of high school completion and a lower employment rate than people without disabilities. In the older cohort, Loprest and Maag (2003) found that the employment rate of people with disabilities is lower than for those without disabilities and that earlier onset is associated with higher employment rates than those whose disability occurred after the

age of 22. Loprest and Maag (2003) also found that receipt of SSDI had the largest negative impact on the probability of a worker with disabilities returning to work, followed by disability severity.

Research on the likelihood of a worker with a disability returning to work and the length of time it takes to complete the job reentry process takes into account biological, psychological, and sociological factors, as demonstrated by the combination of qualitative and quantitative research presented in this section. TTW and similar employment development programs provide employment outreach and training, but typically do not offer services that resolve the biological, psychological, and sociological factors that also present barriers to obtaining stable employment and affordable health care.

# 1.3 Consolidation of the Health Insurance Industry

The third barrier to access to health care among people with disabilities is the consolidation of market share within the health insurance industry, which has reduced competition from smaller carriers and increased health insurance premiums, copayments, and coinsurance fees (Robinson, 2004). In 38 states, the largest health insurance provider is responsible for one-third or more of health care consumers; and in 16 states, the largest health insurance provider is responsible for more than half of individual health insurance recipients, with Blue Cross and/or Blue Shield being the largest health insurance company in all states except California and Nevada (Palmisano, 2007).

The Herfindahl-Hirschman Index (HHI), a measure of market concentration, is calculated by squaring the market share of each firm in a given market and summing the result from each one. A high market concentration signals low market competition. If there were one health insurance company in a given market, it would have 100 percent (monopoly) market share with an HHI of 10,000, while in a market with dozens of health insurance companies, each one would have a relatively small share of the market, resulting in a high level of competition among firms. For example, the Federal Trade Commission and Department of Justice threshold for low-level antitrust concern is an HHI of 1,000. An HHI of 1,000 - 1,800 signals a moderate level of antitrust concern, and an HHI greater than 1,800 signals a high level of antitrust concern (i.e., high market concentration and low market competition). In 2002-2003, only three state health insurance markets had an HHI below 1,000, 12 were between 1,000 and 1,800, and 34 exceeded 1,800. In 2002, the national health insurance HHI average was 2,631 (Borsch & Huynh, 2004), indicating a high concentration of market share and low market competition.

Economic theory suggests that the effect of high market concentration and low market competition is price escalation, which causes further disadvantages for people with disabilities due to their disproportionately high representation among poor and lower socioeconomic status groups. As reported by Borsch and Huynh (2004), health insurance premiums, co-payments, and coinsurance fees rose faster than the average rate of growth in operating expenses and medical costs from 2000 – 2003. During this same period, four of the five largest health insurance plans increased their profit margins from 50- 100 percent (Borsch & Huynh, 2004; Robinson, 2004).

High market concentration allowed existing health insurance companies to dominate growth and innovation in the industry, create barriers to market entry, facilitate hospital and provider consolidation, and render advocacy on the part of employers that subsidize health insurance coverage largely ineffective (Borsch & Huynh, 2004; Palmisano, 2007). Most importantly, market share consolidation affects consumers differently, as people with certain disabilities who are disproportionately represented in the secondary labor market are much less likely to be offered and/or be able to afford health insurance coverage, due to increases in the cost of premiums and other medical expenses.

In the following section, we provide empirical evidence of the economic and occupational inequities in the labor market, as well as a brief explanation of a theoretical framework that explains why these inequities exist for people with disabilities.

# 2.0 The Problem of Labor Market Segmentation

Several labor market researchers have demonstrated the extent of occupational segregation among people with disabilities and other marginalized groups (Butler, Johnson, & Baldwin, 1995; Hollenbeck & Kimmel, 2008; Hotchkiss, 2003). In a detailed study on this topic, Hotchkiss (2003) measured occupational segregation among workers with disabilities, workers without disabilities, white workers, and workers of other races both before and after the enactment of the Americans with Disabilities Act (ADA) using the index of dissimilarity (IOD). 9,10 Using general occupational indices, Hotchkiss (2003) reported that 13 percent of "professional" people with disabilities (or their counterparts without disabilities) would have to change occupations to create occupational equality in the labor market. Although two years after ADA went into effect (1995), Hotchkiss (2003) reported a 16.7 percent decline in IOD, occupational segregation among people with mental disorders remained at 38 percent of the professional labor market. 11

Occupational segregation results in a disproportionate number of people with disabilities being allocated to low-wage jobs. Segmented labor market theory explains the differences in job characteristics among three distinct labor market categories (Wilkins, 2003). The **Secondary Segment** provides low-wage, semi-skilled jobs, limited career growth and little or no employee benefits or health insurance coverage. These jobs are located in the fast food, retail, factory-industrial, and semi-skilled service trades and are often part-time (less than 40 hours of work per week). The **Subordinate Primary Segment** of the labor market provides moderate job security, little or no career growth, and limited employee benefits. The Subordinate-Primary Segment includes such jobs as mailroom clerk, messenger, child care provider, receptionist, data entry operator, and telephone surveyor. **Independent Primary Segment** jobs are highly skilled and offer long-term security, career growth, and comprehensive employee benefits (Edwards, 1975; Sousa-Poza, 1998). Most people with disabilities are employed in the Secondary and Subordinate Primary Segments. Those employed in the Subordinate Primary Segment typically have access to employee-subsidized health insurance, but because their wages are considerably lower than their Independent Primary counterparts, it is often unaffordable (Baldwin & Johnson, 1992) (see Figure 2).

Figure 2: Labor Market Segmentation<sup>13</sup>

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<sup>&</sup>lt;sup>9</sup> IOD measures the percentage of members of one group (i.e., the percentage of people with disabilities in occupation A) that would need to switch to another group (i.e., the percentage of people with disabilities in occupation B) in order to desegregate two distinct labor market positions.

<sup>&</sup>lt;sup>10</sup> This approach also has been used by housing sector researchers to assess the extent of racial segregation due to residential redlining (Massey, & Denton, 1993), discrimination among racial minorities, and the exclusion of women from primary labor market occupations (Baldwin, & Johnson, 2000). It has more recently been used by labor market researchers to demonstrate the extent of segregation in the labor market among people with disabilities.

<sup>&</sup>lt;sup>11</sup> Occupational segregation affects other historically marginalized groups. IOD values for PWD are lower than those of women (Hoffman, Rowland, & Carbaugh, 2003), racial minorities (Maume, 2006), and immigrants (Catanzarite, 2002).

Self-employed were excluded from this analysis. People with disabilities who are self-employed are disproportionately located in the secondary labor market. The challenges of secondary labor market workers can be used as a proxy for people with disabilities who are self-employed.

<sup>&</sup>lt;sup>13</sup> From "Disability and American Families: 2000" by the U.S. Census Bureau 2005, *Census 2000 Special Reports*. Copyright 2005 by the U.S. Census Bureau. Adapted with permission of the author.

#### **Secondary Segment Subordinate Primary Independent Primary** Low Stability Moderate Stability High Stability Low Wages •Low-Moderate Wages Moderate to High No Benefits Limited Benefits Comprehensive Benefits •Semi-Skilled Jobs Skilled-Jobs •No to Semi-Skilled Jobs 25% of Workers with 75% of Workers with Disabilities Disabilities

#### U.S. Census Bureau, 2000

An important factor in determining labor market position is growth in socioeconomic status, which has been moderate for people with disabilities relative to the increase in wealth among Americans without disabilities during the past two decades (Hotchkiss, 2003; Schur et al., 2005). Downward mobility for vulnerable groups in the U.S. labor market has been consistently higher than that of the working-age population without disabilities, even when controlling for socioeconomic and human capital variables (Wilson, 2003). Research conducted by Schultz et al. (2004) and Truchon, Fillion, and Arsenault (2008) found that long-term labor market detachment among workers with disabilities has as much to do with individual economic characteristics as the time since onset of the disability, psychological stress, quality of the work environment, and concerns about reductions in SSDI benefits. The longer workers with disabilities remain unemployed and experience further deterioration in functional ability, the less likely they are to reenter the labor market.

In Section 3.0, we summarize the demographic characteristics of people with disabilities, highlighting their socioeconomic status relative to that of people without disabilities.

# 3.0 Demographics and Employment Status of Working-Age People with Disabilities

The 25 million working-age people in the United States with a sensory, physical, mental, or self-care disability (Houtenville, Erickson, & Lee, 2007) are at a considerable disadvantage when compared with the working-age population without disabilities. Working-age people with disabilities have an overall employment rate of 38.5 percent, compared with 83.7 percent for people without disabilities (Bureau of Labor Statistics, 2009). Approximately 38.8 percent of people with disabilities between the ages of 25 and 34 are employed, compared with 87.6 percent of their counterparts without disabilities, a difference of 55.7 percent (Stoddard, Jans, Ripple, & Kraus, 1998). As shown in Table 2, the median income of families with at least one member with a disability is 71.8 percent of the national median income. Median incomes for families with at least one member with a mental or physical disability are 66.4 percent and 67.8 percent, respectively, of the national average.

Table 2: Median Family Income by Disability Type for Families with at least One Member with a Disability

Disability Status of at Least One Family Member	Median Family Income
No disability	\$54,515
Any disability	\$39,155 (71.8%)
Sensory disability	\$38,775 (71.1%)
Physical disability	\$36,950 (67.8%)
Mental disability	\$36,197 (66.4%)

Note. Adapted from "Disability and American Families: 2000" by the U.S. Census Bureau 2005, Census 2000 Special Reports. Copyright 2005 by the U.S. Census Bureau. Adapted with permission of the author.

People with disabilities are more likely to live in poverty and less likely to work in non-management jobs. Specifically, families with at least one member with a disability are 39.8 percent more likely to live in poverty and 25.4 percent and 28.3 percent are less likely to hold positions in management or have a Bachelor's degree, respectively, than their counterparts without disabilities (U.S. Census Bureau, 2007).

The socioeconomic status of people with disabilities is particularly important, as declines in functional limitations are highly correlated with distance above the poverty line and increases in level of education (Minkler, Fuller-Thomson, & Guralnik, 2006).<sup>15</sup> These social and economic disadvantages, however, are somewhat offset by the federally funded subsidized public health insurance programs, discussed in detail in Section 4.0.

<sup>15</sup> Research by Oguzoglu (2007) and O'Donnell (1998) indicates that disability severity explains a large proportion of the variance in labor market participation rates and impacts on employment outcomes among people with disabilities.

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<sup>&</sup>lt;sup>14</sup> McNeil (2000) reported a disability employment rate of 47.3% for the 9.2 million people with disabilities who do not participate in SSDI or Medicare.

# 4.0 Subsidized Health Insurance Programs

In the United States, people with disabilities are more likely to have health insurance coverage than people without disabilities. A 2003 survey found 95 percent of people with disabilities had health insurance coverage (Hanson, Neuman, Dutwin, & Kasper, 2003), while the share of the general population under age 65 without insurance at some point during that year reached 25.4 percent (Rhodes, McPhillips-Tangum, Markhaum, & Klenk, 2008). The precise share of people with disabilities with health insurance coverage is difficult to determine, due in part to how disability is defined. When disability is considered in a restrictive manner, the proportion of insured individuals is higher. The main reason for this is the subsidized public health care system, which *most* individuals with severe disabilities can access both at the state and federal levels. In 2008, 48.1 million Americans were enrolled in Medicaid, of which 8.5 million were people with disabilities (Centers for Medicare and Medicaid Services [CMS], 2009). In 2007, 44.1 million people were covered by Medicare: 36.9 million aged 65 and older and 7.2 million with disabilities (Truffer, Klemm, Hoffman, & Wolfe, 2008).

In the following sections, we discuss the subsidized public health care programs available to people with disabilities, as well as the quality of health care provided by the Medicaid and Medicare programs. We also present the key features of each program and research on their impact on workforce participation among people with disabilities. Finally, we analyze policies designed to overcome the disincentives of these programs.

## 4.1 Medicaid and Medicare

Medicaid is a joint federal-state program designed to increase access to health care for some low-income groups. Each state administers its own Medicaid program, while the federal Centers for Medicare and Medicaid Services (CMS) monitors the state-run programs and establishes requirements for service delivery, quality, funding, and eligibility standards. Medicaid is the largest public health program in the United States (CMS, 2009).

Medicaid is a means-tested program designed to assist people whose incomes are below a certain percentage of the FPL. In 2008, the FPL corresponded to an annual income of \$21,200 for a family of four, although income eligibility requirements vary because states may establish their own. People with significant disabilities may meet the "categorical eligibility" criterion for the Medicaid program. The categorically eligible constitute one of the groups that Medicaid was designed to assist, in addition to children, women who are pregnant, adults in families with dependent children, and people who are elderly.

Not all people with disabilities are eligible to enroll in Medicaid. There are financial requirements that place limits on income and assets in order to determine if an individual falls into the categorically eligible group, even if they have significant disabilities. Federal law requires states to cover the mandatory groups: pregnant women and children under age six with family incomes below 133 percent of FPL, children age six to 18 with family incomes below 100 percent of the FPL, parents below states' July 1996 welfare eligibility levels (often below 50 percent of FPL), and most older people and people with disabilities receiving Supplemental Security Income (SSI)<sup>16</sup>, for which income eligibility equates to 74 percent of FPL for an individual<sup>17</sup> (Henry J. Kaiser Family Foundation, 2008). The federal government

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<sup>&</sup>lt;sup>16</sup> SSI is a welfare program administered by the Social Security Administration (SSA) that provides low-income older people, people who are blind, and people with disabilities with a monthly payment that supplements their income.

<sup>&</sup>lt;sup>17</sup> When SSI was established, 11 states decided to keep their Medicaid eligibility rules because they were stricter than the SSI eligibility rules. These states are mandated to allow older people, people who are blind, and people with disabilities to qualify for Medicaid in the "spend-down" program (Henry J. Kaiser Family Foundation, 2003).

has established Medicaid coverage mandates that the states must follow. States retain the option of providing more generous coverage, but they cannot adopt more stringent standards that would exclude groups protected in the federal mandate, with a few exceptions.

In general, people with disabilities who receive SSI benefits are eligible for Medicaid. SSI recipients must meet certain income and asset requirements to qualify. In addition, they must not work or they may work, but not at a SGA level. In 2009, the SGA level is 980 dollars/month for people who are not blind and 1,640 dollars/month for people who are blind (SSA, 2009). The SGA level is adjusted for inflation annually. In 32 states and in the District of Columbia, Medicaid enrollment is automatic for SSI recipients, while other states require separate enrollments for each program.<sup>18</sup>

Unlike Medicaid, Medicare is a social insurance program administered by the United States government, providing health insurance coverage to people who are 65 and older, certain individuals with disabilities, and people of all ages with end-stage renal disease. Individuals who have worked for at least 18 months of the previous 10 years paying Social Security taxes, who become unable to work due to a disability, can request SSDI. <sup>19</sup> Individuals who have received SSDI payments for 29 months, subsequently, become eligible for Medicare. <sup>20</sup>

Table 3 compares the two programs across a number of features. Of note is the high cost of Medicaid coverage for people with disabilities, consuming 41.8 percent of annual Medicaid expenditures.

In addition to the mandatory Medicaid groups, federal legislation establishes that states may cover the following optional groups: (1) The **medically needy group**: The medically needy program allows people with high incomes to use their high health care expenses to "spend down" their earnings to Medicaid income levels, to qualify for coverage. The medically needy category directly affects many people with disabilities who are high users of health care. (2) The **poverty level group**: States may provide Medicaid to people with disabilities with incomes up to 100 percent of the FPL. (3) The **state supplementary payment group**: Many states supplement the basic SSI cash assistance with state supplementary payments (SSP) to certain SSI beneficiaries and people with incomes too high to qualify for SSI. States can opt to make anyone receiving an SSP automatically eligible for Medicaid. (4) The **Institutionalized Individuals Group**: States may use a special income rule to provide Medicaid to persons in institutions who have too much income to qualify for SSI benefits, but not enough to cover their expensive long-term care. States may set a special income standard of up to 300% of the maximum SSI benefit (U.S. Social Security Administration, 2009).

<sup>&</sup>lt;sup>19</sup> SSDI is a wage replacement program for people with disabilities who have worked and have paid into the Social Security Trust through FICA taxes (U.S. Social Security Administration, 2009).

Medicare coverage consists of four parts. Medicare Part A refers to hospital insurance. Part B consists of supplementary medical insurance (e.g., for doctor visits). In general, Medicare Part A does not require a premium payment, whereas Part B requires a monthly premium payment. In 2008, the monthly premium for Medicare Part B was \$96.40. Medicare Advantage plans provide supplemental assistance to Medicare participants by combining Part A and Part B. Medicare Advantage plans are health plan options that are approved by Medicare but run by private companies. They are part of the Medicare program, and sometimes called Part C. Starting on January 1<sup>st</sup> 2006, a drug prescription plan, Medicare Part D, became available for Medicare beneficiaries.

**Table 3: Comparing Medicaid and Medicare Programs** 

Features	Medicaid	Medicare
Eligibility	Means-tested, persons with disabilities and low income qualify*	Worker must have SSDI, which requires contributions*
Number of Enrollees	48.1 million in 2008 People with Disabilities: 8.5 million	44.1 million in 2007 People with Disabilities: 7.2 million
Cost	\$294.4 billion (in 2005) People with Disabilities: \$ 126.7 billion	\$ 425 billion (in 2007) People with Disabilities: \$49 billion
Funded By	States and federal government	Federal government through payroll taxes
Hospitalization	Yes	Yes, with limits on covered hospital stays
Physician's Visits	Yes	Yes, co-insurance of 20 percent and premium (\$96.40 monthly)
Prescription Drugs	Yes, restrictions vary by state	Yes, with small co-pays
Dental Care	Yes	No
Mental Health Care	Yes	Yes, with deductible and co-payment Higher co-payments for mental health than somatic health care
Long-term Care	Yes	No
Durable Medical Equipment	Yes Medical Necessity Requirement varies by state	Yes Medical Necessity Requirement with co-payments

Created with data from the U.S. Social Security Administration, Board of Trustees (2008).

#### 4.1.1 Quality and Access to Health Care for People with Disabilities with Medicaid or Medicare

Eligibility and enrollment in Medicaid or Medicare is part of the process of guaranteeing health care for people with disabilities. In this section, we examine issues involving the quality and access to services for people with disabilities who are enrolled in Medicaid or Medicare. This analysis focuses on a comparison of the costs of care and scope of coverage of the two plans, the problem of physician participation and access to care, the impact of state differences in coverage in Medicaid and, finally, the deficiencies in the medical care received by patients with disabilities in general.

## 4.1.1.1 Costs and Scope of Coverage

In a direct comparison with Medicaid, Medicare coverage has been considered worse by individuals with disabilities (DeJong et al., 2002). For people with disabilities who require frequent medical care, Medicare's cost-sharing structure poses difficulties. Medicare's cost arrangement works in a similar fashion to private health insurance plans: enrollees pay a monthly premium for Medicare Part B (medical visits) and they also are responsible for co-payments and co-insurance for doctor visits and medical procedures. Medicare enrollees who can afford it may purchase supplemental insurance to cover the expenses that Medicare does not pay for, but such coverage also requires a monthly premium payment (Goodman, Stapleton, Livermore, & O'Day, 2007). Because Medicaid enrollment is restricted to certain groups of low-income people, its payment structure does not include monthly premiums or co-

<sup>\*</sup>Medicaid Buy-in allows individuals to join Medicaid for a fee, even when they are above Medicaid threshold and do not receive SSDI.

insurance/co-payment rates.<sup>21</sup> As a result of the higher out-of-pocket costs for Medicare, enrollees are more likely to delay treatment than Medicaid enrollees (Hanson, Neuman, Dutwin, & Kasper, 2003).

In the disability research field, Medicaid service coverage has been compared favorably to Medicare with regards to meeting the care needs of people with disabilities (Acevedo, Kahn, & MacDonald, 2005; DeJong et al., 2002). Although there is substantial variation across states, with many limitations on the scope of services covered, states are allowed to include coverage benefits that are particularly valuable for people with disabilities. These services include mental health services, personal assistance services, assistive technology and durable medical equipment, and long-term care (DeJong et al., 2002). In addition, states may offer dental and extensive vision coverage under Medicaid. These coverage plans are important since poor dental and vision health have been found to be secondary conditions associated with certain types of disabilities that have a direct impact on quality of life. Medicare does not offer dental coverage, and its vision coverage does not include eyeglass frames and prescription (lezzoni, 2006; Krahn, Hammond, & Turner, 2006).

# 4.1.1.2 Physician Participation in Medicaid and Medicare

While Medicaid does not require significant out-of-pocket expenses compared to Medicare, its enrollees are affected by low rates of physician participation to a much larger degree than Medicare enrollees (Tucker, 2002). Low physician participation affects access to health care, as patients struggle to find physicians and specialists willing to see them. Still, in many crisis situations, Medicaid patients are inadvertently attended to by non-participant physicians, and as a result are burdened with medical bills despite having Medicaid (Taube, Goldman, & Salkever, 1990).

Since its inception, Medicaid has seen a decline in the share of participating physicians. There has been extensive research on the determinants of physician participation in Medicaid. The single most important factor influencing a doctor's decision to accept Medicaid patients is the reimbursement rates Medicaid offers (Perloff, Kletke, & Fossett, 1995; Waidmann, Ormond, & Ahmad, 2008). Delays in Medicaid reimbursement also have been shown to discourage physician participation in the program (Cunningham & O'Malley, 2008). Reimbursement rates vary considerably from state to state, as well as according specialty area and locale of treatment. These somewhat arbitrary reimbursement rules have a direct impact on the quality of care patients receive. Patients may be hospitalized without need because outpatient care is not available due to unprofitable Medicaid rates in some states, while in other states where rates support outpatient services, enrollees are less likely to be unnecessarily hospitalized (Taube et al., 1990).

In addition, research indicates that higher physician practice costs lead to less participation in Medicaid. Generally, primary care physicians are more likely to work from private practices with higher overhead costs than specialists working at hospitals. As a result, primary care physicians, responsible for comprehensive health evaluations and critical for the coordination of care for patients with complex needs, are less likely to participate in Medicaid (Tucker III, 2002). The decline in participation leads to difficulty in finding medical assistance and, potentially, continuity of care. For many individuals with disabilities and/or chronic conditions, continuity of care is crucial to prevent health deterioration and the development of related secondary conditions (Long, Coughlin, & Kendall, 2002).

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A large number of individuals are eligible for both Medicaid and Medicare coverage. This group is referred to as "dual eligibles." Eighteen percent of Medicare beneficiaries are dual eligibles. In general, dual eligibles are people with very low income and high health care needs, and use more Medicare services than other Medicare groups. Their health care costs are split between Medicare and Medicaid. Medicare covers their basic health needs (hospitalizations and physicians visits), and Medicaid pays for their Medicare premiums, in addition to specialized care that Medicare does not cover, such as long-term care (Henry J. Kaiser Family Foundation, 2004).

Physician participation in Medicare also has experienced a decline, but not as severe as Medicaid's, mostly because Medicare reimbursement rates are closer to private insurance rates (Medicare Payment Advisory Commission, 2002). In a sample of 631 dermatologists, for instance, acceptance rates for Medicare patients was 85 percent, similar to the 87 percent rate of acceptance for private health insurance, whereas Medicaid patients were accepted only 32 percent of the time (Resneck, Pletcher, & Lozano, 2004). Still, there is evidence that Medicare participation may be in decline faster in certain areas of the country,<sup>22</sup> and that political debate over reimbursement rates pushes doctors to leave the program rather than live with the uncertainty (Jenkins, 2008).

# 4.1.2 Physicians Are Not Always Prepared to Provide Health Care to People with Disabilities

Even when people with disabilities receive public health insurance coverage and visit a doctor who participates in Medicaid or Medicare, they face other challenges. First, not all physicians report complying with ADA regulations with regard to physical access to the facility; for example, as many as 22 percent of people with disabilities interviewed in the Los Angeles area reported accessibility problems (Kirschner, Breslin, & Iezzoni, 2007). Many doctors' offices also do not have accessible examining tables and other equipment, which has resulted in litigation. In addition, research indicates that few additional accommodations are available, such as the use of an interpreter or special assistive technology (Grabois, Nosek, & Rossi, 1999). Looking at 12,769 Medicare beneficiaries aged 65 or older, researchers found that those with a functional limitation are substantially more likely to report difficulties getting access to doctors and specialists and follow-up care. These difficulties increased as the number of functional limitations increased (Hoffman et al., 2007; Jha, Patrick, MacLehose, Doctor, & Chan, 2002).

Researchers have paid close attention to the inadequacy of the treatment provided to patients with disabilities. Recent research estimates the quality of care provided by physicians to patients with disabilities by comparing it with the medical community guidelines and heath care services provided to patients without disabilities. Medicare beneficiaries with functional limitations were shown to receive less preventive care measures, such as pap smears, blood tests for prostate cancer, and digital rectal prostate exams. These preventive care measures also declined as the number of functional limitations increased (Hoffman et al., 2007). However, there is also some evidence that, although women with disabilities are less likely to receive mammograms and pap smears at the recommended intervals, they are more likely than patients without disabilities to receive flu immunizations, cholesterol screening, and colorectal screening in the recommended intervals.

Among the factors that lead to higher rates of receipt of preventive care is private health insurance coverage. Public health insurance beneficiaries were less likely to receive three types of cancer screening when compared with women with some private insurance, while those in Medicaid or Medicare were slightly more likely to get a flu shot and cholesterol screening (Wei, Findley, & Sambamoorthi, 2006). Similar research indicating less likelihood of receiving of pap smears and mammograms for women with disabilities suggests that financial problems and health insurance limitations are to blame for the poor-quality care (Chevarley, Thierry, Gill, Ryerson, & Nosek, 2006). At least one study in France, which also shows a lower likelihood for breast cancer screening for women with disabilities, identified feelings of discomfort by doctors when treating persons with disabilities as one reason why they receive low-quality care (Verger et al., 2005). Researchers also have shown that

The predicament in rural areas is related but somewhat different. While rural areas face health professional shortages and a smaller number of hospitals, the rural health care system relies disproportionately on public reimbursement, especially

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smaller number of hospitals, the rural health care system relies disproportionately on public reimbursement, especially Medicaid (Ziller, Coburn, Loux, Hoffman, & McBride, 2003). As a result, people with disabilities living in rural areas face a severe shortage of health care professionals, but are more likely to receive Medicaid than their urban counterparts (RUPRI Rural Health Panel, n.d.).

lower rates of appropriate screening lead to lower chances of a correct cancer diagnosis and, consequently, higher mortality rates (McCarthy et al., 2006; McCarthy et al., 2007).

## 4.2 Subsidized Public Health Insurance and Work Incentives for People with Disabilities

People with disabilities must be deemed disabled by SSA's standards in order to be eligible for cash subsidies (i.e., SSI or SSDI) and health care benefits (i.e., Medicaid or Medicare). The SSA determination of disability is considered strict, as it establishes that a person with a disability must be unable to perform SGA to qualify (SSA, 2009). As a result, only individuals with more severe impairments are entitled to assistance (World Disability Institute, 2003).

More than Medicaid beneficiaries, Medicare recipients face strong disincentives to return to work. SSI benefits are calculated using a sliding scale for recipients who choose to work (National Council on Disability, 2005). For SSDI recipients, the most powerful disincentive to work is the sudden loss of all cash benefits associated with earnings above SGA level, the so-called cash cliff. In order to mitigate the disincentive to work, SGA levels have been annually adjusted since 2001 to account for wage growth. This measure, at least, adjusts the level of earnings that a SSDI recipient can have and keep the cash benefit. Still, the disincentive to work is strong, since the SGA level is fairly low.

Economists have long been concerned with the impact of disability benefits on the labor force. In particular, they have looked into the question of whether the cash benefits lead people to withdraw from the labor market. In other words, researchers wanted to measure whether disability benefits make people who otherwise would continue working to stop working. Recent research has attempted to address the methodological flaws of earlier analyses. In particular, researchers must find a way of assessing the impact of benefit size on work efforts, while controlling the endogeneity involved in benefit determination. Endogeneity is born out of the fact that benefit levels of disability insurance are calculated based on past earnings, and past earnings are a reflection of one's past work decisions. In other words, a direct analysis of the impact of benefit size on work decisions cannot use benefit size directly to assess the connection, as benefit size is affected by previous work decisions. Endogeneity problems, when not addressed, may create inflated and statistically significant coefficients. These results are biased. Unsurprisingly, early models in the 1980s found extremely high correlations between benefit levels and labor force withdrawal (Parsons, 1980; Slade, 1984).

More recent research has found ingenious ways to try to overcome the endogeneity problem and provide unbiased coefficients. One study (Gruber, 2000) looked into the impact of a sudden increase of disability benefits in Canadian provinces in 1987 (36 percent), and compared its impact with the conditions in Quebec, the one province in which benefits did not increase but were already considerably higher. In fact, the benefit increase was meant to unify the rates across the entire country. By using the two comparison groups, and assuming that the only difference between the two groups was the difference in benefit rates, Gruber believed his results avoided the endogeneity problems of previous analyses. He estimated that the 36 percent rise in disability benefits led to a rise in nonemployment of 11.5 percent among people with disabilities, which is considerably lower than the estimates of earlier studies. The author speculated on the impact of his findings on the American context. He argued that disability benefits were much higher in the United States than in Canada and therefore encourage nonemployment. He suggested that a system with lower benefits but lower denial rates for applicants would produce better results in the United States. Looking at earlier Canadian data, <sup>23</sup> Campolieti (2004) found a lesser magnitude impact. Finding a smaller change in benefits, he posited that the difference is

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These researchers used Canadian data in part because the disability insurance program in that country had institutional differences in Quebec, in a way that was suitable for comparative analysis. In the United States, the disability insurance program is federally mandated, without such institutional differences.

explained by the different set of rules regarding disability insurance in the period he looked into, the early 1970s. At that time the rules were stringent and the denial rate was higher, and consequently, he argues, the increase in benefit levels did not result in labor force withdrawal, since individuals knew it would be hard to qualify for those benefits. The "screening regime" for disability insurance is central to this analysis, and there is empirical evidence that in periods of more lax screening rules, nonparticipation in the labor force increased for people with disabilities.

In the early 1990s, labor force participation for people with disabilities decreased in the United States. While some blamed the rules established by the Americans with Disabilities Act of 1990, there is strong evidence that the decline started before the law came into effect in 1992 (Bound & Waidmann, 2002). They note that the growing numbers of disability insurance participants account for the decline in labor market participation by people with disabilities. Supporting Gruber's findings, the impact is stronger among low-wage groups, as the salary replacement rate of the benefits is higher for them. In other words, the payoff for work is lower among low-skill, low-wage workers (Stapleton, Goodman, & Houtenville, 2003).

Chen and van der Klaauw (2008) estimate that the labor force participation of beneficiaries of disability insurance would be 20 percent higher if they did not receive the benefits, leading to a reduction in hours of work of at most 30 hours monthly. A study of the prevalence of part-time work among SSI and SSDI recipients found that, controlling for disability type, degree of job supervision required, and related factors, the receipt of cash benefits was the overwhelming reason for recipients to take part-time instead of full-time jobs (Kruger, Elinson, & Milfort, 2006). One typical suggestion to overcome the disincentive to work that disability cash benefits entail would be to increase the earning limits these programs establish. However, this solution has been criticized on the basis that a more generous disability benefit program would lead people not currently receiving benefits to begin doing so (Williamson, Hoynes, & Moffitt, 1996, as cited by Ross, 1997).

In addition to the cash benefits, subsidized health insurance poses a disincentive to return to work for people with disabilities. Between 2003 and 2004, only 0.5 percent of SSDI beneficiaries had a change in cash benefit status because of employment (World Institute on Disability, 2006). One of the main reasons SSI and SSDI recipients with disabilities cite for not going back into the job market is fear of losing their publicly subsidized health insurance coverage (Hanes, 2000; Hill, Livermore, & Houtenville, 2003; Kruger et al., 2006; O'Day, Stapleton, & Horvath-Rose, 2007). This is hardly surprising since many - but not all - types of disabilities lead to high health care usage and costs. DeJong et al. (2002) found that only 3 percent of respondents with mobility impairments reported no health care expenditures that year, compared with 16 percent among respondents without similar impairments. The study found that the median annual expenditure on health care for people with mobility impairments was \$2,489, compared with a median of \$420 for the sample without impairments. Similarly, Hwang and his colleagues found that individuals with chronic conditions (e.g., diabetes) spend substantially more outof-pocket for health care, than individuals without any chronic conditions (Hwang, Weller, Ireys, & Anderson, 2001). As a result, for frequent users of health care, the possibility of losing benefits has a clear and serious impact on their well-being and finances. In sum, both the loss of cash benefits and health care insurance pose a great disincentive for people with disabilities to look for gainful employment.

In looking for ways to stimulate employment among people with disabilities enrolled in public health coverage programs, policy makers at the state and federal levels in the United States have begun to address the rational fear that people with disabilities have of losing benefits due to work through programs that address work incentives and promote employment among people with disabilities.

#### 4.2.1 The Section 1619(b) Program

It is federally mandated, under Section 1619(b) of the Social Security Act, that states provide Medicaid coverage to individuals who are eligible for SSI, but whose incomes are too high to continue to receive SSDI. The Medicaid coverage lasts as long as earned income remains under a state threshold, and the earnings are the only reason for the end of SSI assistance. This work incentive for people with disabilities applies to individuals whose earnings are below the value of the sum of SSI and state supplemental payments.

A significant challenge in evaluating the impact of this intervention is under-enrollment. In 1999, only 1.9 percent of working age SSI beneficiaries were in the 1619(b) group (Newcomb, Payne, & Waid, 2003, as cited by Wiener, 2003). One factor contributing to the low enrollment in the program has been attributed to a lack of knowledge and understanding among the target audience of the program, but perhaps most importantly, among the professionals who counsel people with disabilities through the Medicaid and SSI systems. There are significant problems of communication between the SSA and state Medicaid eligibility workers in ways that affect critical aspects of the implementation of the program. In particular, the difficulties in reporting income, a critical qualifying factor for Section 1619(b) benefits, have been presented as an obstacle to implementation (Center for Workers with Disabilities, 2002).

#### 4.2.2 Ticket to Work and Work Incentives Act of 1999

The Ticket to Work and Work Incentives Improvement Act of 1999 (TTWWIA) was designed to remove barriers that discourage people with disabilities from returning to work. In particular, it seeks to relieve concerns over losing public health care coverage once they reenter the labor market. The TTWWIA is designed for both SSDI and SSI beneficiaries. It aims to provide better access to rehabilitation, support, and vocational services; greater individual choice in selecting an employment service provider; protection of medical health care coverage during and after return to paid employment; increased participation in competitive employment; and an opportunity to reduce or end dependence on SSA payments as the sole means of income and health care (Gimm, Davis, Andrews, Ireys, & Liu, 2008; Stapleton et al., 2008).

The TTWWIA improved the Extended Period of Eligibility (EPE), which provides an additional safety net beyond the Trial Work Period (TWP) for people with disabilities who attempt to return to the job market without losing eligibility to their cash and health care benefits. In addition, the expedited reinstatement provision provides immediate reinstatement of cash benefits and health care coverage if an SSDI beneficiary's disabling condition recurs and the person can no longer work, when both the TWP and EPE options have expired. The TTWWIA also allows states to institute more generous eligibility rules for their Medicaid Buy-in programs (Kruger et al., 2006).

#### 4.2.3 Medicaid Buy-in (MBI)

In an explicit attempt to assuage concerns about the loss of health care coverage due to work, the Balanced Budget Act of 1997 gave states the option to establish a "buy-in" to Medicaid eligibility for people with disabilities whose countable income made them ineligible for Medicaid (Blanck et al., 2007). The Buy-in program was created as an incentive for people with disabilities to go back to work. It decouples the access to Medicaid health coverage from the cash benefits (Hanes & Folkman, 2003). The TTWWIA allowed states to expand their MBI eligibility rules, promoting the dissemination of the program.

As of 2008, more than 90,000 individuals in 40 states were covered under this new eligibility group. State governments have substantial autonomy with regard to the eligibility requirements in their MBI programs, not unlike Medicaid itself (Gimm et al., 2008). As a result, there are differences in income and

asset requirements for eligibility, program implementation, and premium payment. The manner in which the program counts income levels varies, as many states include spousal income and unearned income, while others assess only individual income. As a result, the pool of potential beneficiaries varies between states (Goodman & Livermore, 2004).

In 2008, Mathematica Policy Research completed a comprehensive analysis of state MBI programs comparing the impact of different enrollment rules on program implementation. The researchers found that the Medicare grace period<sup>24</sup> was the single most important factor affecting enrollee employment in MBI programs, with shorter grace periods leading to higher levels of employment. In addition, strict standards to check for the enrollee's employment status positively affected employment levels among MBI program participants. States that reached out for potential enrollees more aggressively saw more substantive growth in enrollment (Gimm et al., 2008).

In an expansive review of the research of state MBI programs, Goodman and Livermore (2004) highlight some flaws in the programs. The authors found that a substantial number of MBI enrollees are unaware that the program allows them to have higher earnings than Medicaid. It is clear that the impact of the program on employment of people with disabilities will only follow if beneficiaries are informed of the rules regarding earnings for MBI. The authors also point out the long-term goal of lifting people with disabilities out of poverty through work may create other problems. They note that if individuals accumulate assets while enrolled in MBI end up losing their jobs - or turning 65 - they could be no longer eligible for Medicaid. Once again, the fact that certain types of disabilities require high health care use makes the risk of losing health care in the future critical for people with disabilities.

The empirical evidence on the effectiveness of MBI also raises important concerns. A conclusive assessment of the effectiveness of the programs must include an analysis on whether the de-linking of Medicaid coverage from employment status for people with disabilities has in fact achieved the goal of fostering employment and higher earnings. One way to assess the impact of MBI on employment is to evaluate the earnings of comparison groups of individuals who did and did not enroll in order to determine if the increase in earnings after enrollment was due to MBI incentives or to other factors. Few studies have looked at the earnings patterns of individuals with disabilities who enrolled in MBI and compared those to control groups who did not enroll. Those studies appear to indicate that MBI has had little impact on earnings (Hanes, Edlund, & Maher, 2002; Salahuddin, 2003, as cited by Goodman & Livermore, 2004). The low levels of earnings among participants has been seen as a result of the persistence of the fear of losing cash benefits, especially among those receiving SSDI (Hall, 2003). Research also has shown that counselors have not provided eligible MBI candidates with the most accurate information regarding the program (Hall & Fox, 2004).

# 4.2.4 The Demonstration to Maintain Independence and Employment (DMIE)

The Demonstration to Maintain Independence and Employment (DMIE) was authorized by section 204 of the TTWWIA. The DMIE allows states to develop projects aimed at disability onset prevention. It allows states to provide health insurance coverage for individuals with potentially disabling conditions, but who do not meet the disability requirements of SSA and who, therefore, do not qualify for Medicaid or Medicare. The DMIE goal is to rigorously assess whether access to health care can prevent individuals with potentially disabling conditions from leaving the labor market and receiving disability benefits (Hall & Moore, 2006).

<sup>&</sup>lt;sup>24</sup> The grace period allows beneficiaries to work for a period of 90 days and earn income that exceeds Medicare limits. This allows beneficiaries to reenroll should they become unemployed during the grace period.

The DMIE legislation allows states to choose target populations for coverage, but their demonstration programs must include a control group not receiving the intervention. Five states (Mississippi, Hawaii, Kansas, Minnesota, and Texas) and the District of Columbia have grants to operate DMIE demonstration projects.

- The Hawaii DMIE (2008 implementation), which uses random assignment, provides pharmacist counseling, life coaching, diet and exercise counseling, and employment support services to treatment group participants. The key outcomes of this effort include: improvements in employment, earnings, health status, and independence from SSDI and other subsidized programs.
- Both Minnesota (2006 implementation) and Texas (2007 implementation) have established public/private partnerships to provide comprehensive behavioral health insurance to working adults at risk of becoming disabled. The Minnesota and Texas supplement employer-sponsored health insurance coverage and provide full coverage to low income uninsured DMIE participants.
- The District of Columbia and Mississippi (2002 implementation) DMIEs provide Medicaid benefits, including anti-retroviral drug therapy to HIV infected residents who not are yet disabled under SSA determination guidelines
- The Kansas, DMIE (2006 implementation) offers "wrap-around" services to the existing high-risk
  pool in the state, to lower out-of pocket expenses, and provide "enhanced" benefits beyond
  Medicaid services. The services provided by these programs include: home visits for assistance
  with personal care, exercise training, individual psychotherapy, and case management. (CMS,
  2009).

Preliminary results from the Kansas DMIE project indicate that the 200 participants who are receiving the wrap-around coverage are experiencing less pronounced decline in their overall health than the control group, at least initially supporting the goals of preventing individuals from starting to receive disability benefits (Hall & Moore, 2006). The early findings also indicate that participants in the high risk pool have important unmet or under-provided health care needs, as the wrap-around vision and dental coverage experienced high demand (Hrybyk, 2007).

While there is no publicly available impact or cost-to-benefits data on DMIE programs, their focus on high-risk populations requires an intensive case management component in order to maintain expected program enrollment and service utilization rates. This problem has already been reported by TTWWIA researchers as a barrier to meeting expected outcomes (Thornton et al., 2007). Both TTWWIA and DMIE are promising efforts that may have a moderate impact on the employment rates and earnings of people with disabilities in high-risk categories. In contrast, stronger outcomes have been found by the Massachusetts MBI program, which does not provide the range of support services that TTWWIA and DMIE offer, but appears to serve a less disadvantaged population.

## 4.2.5 Health Insurance Premium Payment Program

The Health Insurance Premium Payment (HIPP) program was established in 1990 as part of the Omnibus Budget Reconciliation Act. It aims to decrease Medicaid costs by encouraging Medicaid beneficiaries to get employer-sponsored insurance. The HIPP program may pay for the cost of private health insurance premiums, when it is found to be cost-effective. HIPPs are state-run programs that can provide Medicaid beneficiaries with access to private employer-sponsored health care coverage through premium payments. In addition, under HIPP, the beneficiary still can use Medicaid for any services not covered under the employer's plan in wrap-around services, including co-pays and deductibles, of the

employer-sponsored plan. The costs of premiums, wrap-around services, and administration of the program are not to exceed the costs of enrollment in Medicaid alone (Acevedo et al., 2005).

The HIPP program has not been successful as enrollment has been low and cost-savings are hard to determine due to the complexity of calculating administrative costs for each participant (Acevedo et al., 2005). The lack of employer-sponsored coverage for employed individuals covered by Medicare is an obvious reason for the low enrollment in HIPP (Williams, 2003). As Acevedo et al. (2005) noted, it is often difficult for program administrators to identify potential enrollees, as people with disabilities fear losing their Medicaid benefits and may not disclose that they are eligible for employer-based health insurance. Pennsylvania is one state that has seen a large enrollment in its HIPP program. The state requires Medicaid beneficiaries to enroll in HIPP as a condition of continued eligibility for Medicaid as long as doing so is cost-effective. As with some of the MBI programs, enforcement of the requirements of the HIPP program in Pennsylvania appears to have produced a more successful program. It has yet to be determined if, in addition to the mandated savings, the HIPP program provides better health care services to participants and is more successful in keeping individuals with disabilities in the workplace.

# **5.0 Promising Practices**

In this section, we summarize programs that appear to alleviate two of the three system-level factors that inhibit access to health care for people with disabilities discussed in Section 1.0, including the consolidation of market share in the health insurance industry and the problem of SSI employment disincentives.<sup>25</sup> We also provide examples of large businesses that provide affordable comprehensive health insurance coverage to their employees, which alleviate *some* of the treatment-level factors included in the bio-psycho-social model.<sup>26</sup>

# **5.1 Collaborative Relationships**

We identified three collaborative working relationships among insurers, providers, and employers that appear to improve access to health care for people with disabilities. These efforts include an intervention and/or mandate by state and/or local government to both create and ensure the success of the partnership, although the government's role has been limited to oversight and facilitation. The first type of partnership is based on the *pay-for-performance* (P4P) model, which requires insurers, providers, employers, *and* employees to play important roles in the cost-containment process (Adler, 2005; RAND Corporation, 2007). The second form of collaborative partnership is *reinsurance*, which several states have implemented to decrease the cost of health insurance coverage by sharing the cost of high-risk individuals. The third type is called *community-based financing* (CBF). CBF is based on the concept of collective action and organizing at the grassroots level in which communities form "groups" of health insurance consumers that negotiate with insurers, employers and providers to provide members with affordable health insurance coverage (Bennett, 2004).

<sup>&</sup>lt;sup>25</sup> We also identified several programs that attempt to mitigate the problems associated with labor market and occupational segregation, which was the other factor described in Section 1.0 that inhibits access to health for people with disabilities. But because these programs prepare participants for work in the secondary labor market, they are unlikely to expand health insurance coverage in any demonstrable way and certainly do not resolve the problems of labor market and occupational segregation that affect most marginalized populations. Labor market and occupational segregation is due, in part, to an ingrained process of social exclusion that targets society's "out-groups" and is a key component of the system of social stratification in the United States that creates obstacles for certain groups of people that affect their life-chances, including their career trajectories and social, occupational and economic mobility (Beeghley, 2008).

<sup>&</sup>lt;sup>26</sup> We define promising practices as organizational and procedural innovations in health care that *appear* to expand the availability of health insurance coverage to people with disabilities (PWD). The evidence underlying a promising practice is limited to anecdotal reports of program efficacy or quasi-experimental agency-based research and evaluation findings. By contrast, evidence-based practices, which we define as theoretically and empirically grounded approaches that improve access to health care for PWD, require rigorous, controlled research studies conducted by a third-party (Elstein, 2004).

## 5.2 Pay for Performance Partnerships

P4P models share the risk and reward of cost-containment among insurers, employers, and employees. For example, Maine's Pathways to Excellence (PTE) program rewards hospitals that provide cost-effective high quality health care services. Under PTE, performance is measured through patient satisfaction surveys, patient safety statistics, and clinical and cost effectiveness studies. In Maine, 10 participating hospitals pay .05 percent of routine employee health care costs, which are placed in a setaside fund with "guarantee" and "bonus" levels assigned to four quality measures related to patient satisfaction and hospital cost-containment. Employers also pay an average of \$8,348 each year to fund the program. Employees are expected to limit their use of high-cost services and benefit from lower health insurance premiums and other fees (Adler, 2005; RAND Corporation, 2007). Each participating hospital earns points for meeting designated performance levels and receives a percentage of the setaside fund for performing at the quarantee or bonus levels. In a recent pilot study by the Maine Health Management Coalition, six of the 10 participating hospitals met their bonus performance levels and received an average of \$14,941 from the set-aside fund, while the other four hospitals received an average of \$3,629 for performing at the guarantee level. The Maine PTE program redistributes resources to employers and hospitals in order to create a collaborative working relationship that leads to reductions in the cost of health care while maintaining a high level of quality health care, with the ultimate goal of making health insurance coverage more affordable (Fong, 2007).

#### 5.3 Reinsurance Partnerships

Reinsurance insures insurance companies in exchange for meeting obligations beyond a specified amount. Recently, the concept of government-subsidized reinsurance has been used to improve health insurance coverage rates by asking private health insurance providers to pay a premium in exchange for state subsidized reinsurance. Some states fund their reinsurance programs fully and do not require a premium to be paid by the insurance companies. The intended effect of public reinsurance programs is a reduction in health insurance coverage costs to the consumer and improvements in coverage rates of employees in small employers and self-employed individuals. This reduction is achieved through a state-subsidized reinsurance program, which protects private insurance companies from financial losses due to high-cost cases, by spreading the risk of high-cost claims among insurers in the local market (Bovbjerg, Garrett, Clemans-Cope, & Masi, 2008).

Connecticut and Idaho have mandatory Small Employer Health Reinsurance Programs. All private health insurance companies in these states are enrolled in the program. A provision of the Connecticut reinsurance program requires private insurance companies to make a decision within 60 days of enrolling a new employee of a small business as to whether it will pay all claims for the new employee or relegate certain claims to the reinsurance program. If the private insurer chooses the latter, it is required to pay a premium to the reinsurance program. In the event that claims from the recently enrolled employee exceed the amount of the premium, the state collects an *equal share* of losses from all of the private insurance companies, which is intended to keep health care costs down. In Idaho, all insurers in the state pay a premium tax which is contributed to the reinsurance program. Insurers also pay reinsurance premiums set by a board of directors comprised of insurance companies and local business leaders. Insurers also pay the first \$5,000 of claims and then the reinsurance program covers 90 percent of future claims (Wikler & Fish-Parcham, 2008). In some states, enrollment is limited to high-risk pools and low-wage workers (i.e., Connecticut, Idaho, New York), while others (i.e., Arizona, New Mexico) cover small groups and self-employed workers in need of affordable health insurance coverage (Chollet, 2005).

Reinsurance programs do run the risk of "adverse selection," through which a disproportionate percentage of high-risk cases, relative to normal risk cases, are covered and thus premiums rise to

unexpected levels. It is recommended that reinsurance programs have high insurer and individual participation rates, enroll only full-time workers, and utilize available public health care subsidies for the highest risk groups in order to maintain an efficient and affordable program (Bovbjerg et al., 2008).

# 5.4 Community-based Financing Partnerships<sup>27</sup>

One of the more intriguing efforts designed to expand access to health care is community-based financing, which enrolls uninsured people into health insurance plans and reduces the cost of care by minimizing the use of high-cost health care services among its members. Under the W.K. Kellogg Foundation's Community Voices: HealthCare for the Underserved grant program, New Mexico, Michigan, Texas, North Carolina and California have created innovative cost-saving initiatives in lowincome counties with high-risk uninsured populations. For example, in New Mexico, the University of New Mexico's Health Sciences Center partnered with local county governments to create a network of community-based health centers called First Choice Community Health.<sup>28</sup> First Choice was created to reduce the widespread use of high-cost health care (e.g., emergency room visits rather than communitybased health clinic visits), a shortage of primary care physicians, and dissatisfaction among providers who received low reimbursement rates for subsidized consumers. The program serves the medically indigent and working poor with incomes below 235 percent of the FPL who are not eligible for Medicaid or other subsidized public health programs. First Choice provides outpatient care, inpatient care, physician office visits, and access to primary care health clinics. In addition, the program offers reduced out-of-pocket costs using formulary pharmaceuticals and a 24-hour health telephone hotline triage system. First Choice reduces co-pays by increasing participants' use of primary care services. As a result, the average number of specialty care visits declined from .85 to .68 per participant as did the average number of emergency department and urgent care visits, which declined from .38 to .35. The number of in-patient hospital days per 1,000 member years also dropped from 331.80 to 278.80 (Economic and Social Research Institute, 2001).

#### 5.5 MassHealth

We selected the Massachusetts health care system (MassHealth) as a promising practice because it offers universal coverage, includes programs for low-income people with disabilities, and provides a variety of health care and auxiliary services. Although 43 states have Section 1115 waivers to design and implement health insurance programs for low-income residents, the Massachusetts program was the first to use the Section 1115 waiver to implement a required universal health care system that offers coverage to all uninsured residents of the state. MassHealth combines Medicaid and its State Children's Health Insurance Program (SCHIP) to serve low-income residents under the age of 65, including low-income people with disabilities and the long-term unemployed. MassHealth does not have asset limits for people under the age of 65, although the cost of health care and coverage policies vary based on income, health status and health history. Three separate MassHealth programs have income eligibility requirements to ensure universal coverage and basic to comprehensive health care services (Massachusetts Executive Office of Health and Human Services [EOHHS], 2005).

Research has shown that identifying uninsured families and helping them navigate the public health subsidy enrollment process increases access to health care for under-served groups (Manos et al., 2001).

<sup>&</sup>lt;sup>28</sup> First Choices is funded by Medicaid, county resources, the University of New Mexico Management Care Plan Funds, federal disproportionate share hospital funds and the W.K. Kellogg Foundation grant.

<sup>&</sup>lt;sup>29</sup> MassHealth requires people with disabilities to have a certification of legal blindness from the Massachusetts Commission for the Blind, a disability determination by the Social Security Administration, or a disability determination by the state's Disability Determination Unit to be eligible for targeted programs.

- CommonHealth provides health insurance to adults aged 65 and older with disabilities whose incomes are 100 150 percent of FPL. Residents with incomes from 150 to 299 percent of FPL pay a monthly premium. All participants pay copayments for prescription pharmaceuticals.
- Commonwealth Care provides health care to residents at or below 300 percent of the FPL who
  are ineligible for CommonHealth (e.g., an undocumented resident of the state). Commonwealth
  Care members get free or low-cost health care coverage through local managed care plans with
  premiums based on income; there is no monthly premium for people with incomes at or below
  the FPL.
- Commonwealth Choice was created for uninsured adults who are ineligible for MassHealth, CommonHealth, or Commonwealth Care and have incomes above 300 percent of FPL.
   Commonwealth Choice participants choose from six private health insurance providers with premiums subsidized by the state according to earnings guidelines.

Massachusetts is one of the more generous states in terms of meeting the health care needs of people with disabilities. The state provides supplemental social security income to all elderly people and to individuals of any age with disabilities on SSI. There are close to 190,000 adults with disabilities on SSI in Massachusetts, 92 percent of whom have incomes below 133 percent of the FPL. Most are enrolled in CommonHealth, which serves employed people with disabilities through a Medicaid Buy-in option. About one-half (49 percent) of people with disabilities enrolled in MassHealth are disabled due to mental Illness, 31 percent have physical or sensory disabilities and 13 percent have intellectual disabilities. About one-half have multiple chronic disabling conditions. Spending on people with disabilities increased from \$1.3 billion in 1999 to \$1.9 billion in 2003, representing a 45 percent increase and average annual growth of 10 percent. Close to one-half of people with disabilities have other health care coverage (mainly Medicare), which supplements MassHealth and fills in with mental health care coverage, durable medical equipment and personal assistance services (Massachusetts Medicaid Policy Institute, 2004). The state also offers three programs for people with disabilities, including the Kaileigh Mulligan Home Care Program, Adult Family Care and Group Foster Care (Masschusetts EOHHS, 2005).

Table 4 below compares the federal/state programs providing health care for individuals and families with disabilities in Massachusetts.

**Table 4: Federal/State Health Care Access Programs in Massachusetts** 

Program	Features	Target Group	Eligibility Requirements	Coverage
Mass- Health	<ul> <li>Form of Medicaid in Massachusetts</li> <li>Combination of Medicaid + SCHIP</li> <li>Expenses shared by federal/state</li> </ul>	<ul> <li>Poor</li> <li>Pregnant</li> <li>Elderly</li> <li>With disabilities</li> <li>HIV/AIDS positive</li> <li>Children</li> <li>Unemployed</li> </ul>	<ul> <li>Income relative to FPL</li> <li>Immigrant status</li> <li>Need-based program</li> <li>% of income relative to FPL dependent upon category of recipient</li> <li>Income limits</li> <li>Asset limits for some</li> </ul>	<ul> <li>SSI beneficiaries below income limit of \$36,056 (2008)</li> <li>SSDI recipients</li> </ul>
Common- Health	Medicaid Buy-in program in Massachusetts     Premiums based on a sliding fee scale dependent on income	<ul> <li>Working adults with disabilities</li> <li>Children with disabilities</li> <li>Non-working adults with disabilities</li> </ul>	<ul> <li>Income above MassHealth limits</li> <li>Working adults must work at least 40 hours/month or more</li> <li>Monthly premium goes up as income increases for working adults</li> <li>Substantial one time deductible + premium for nonworking adult</li> </ul>	<ul> <li>SSI beneficiaries above income limit of \$36,056 (2008)</li> <li>SSDI recipients</li> </ul>
Common- wealth Care	<ul> <li>Subsidized health care coverage</li> <li>Choice of managed health care plans</li> </ul>	<ul><li>Low income</li><li>Uninsured</li></ul>	<ul> <li>19 years or older</li> <li>Ineligible for Medicare or MassHealth and other programs</li> <li>Premium dependent on income</li> <li>Income below 300% of FPL</li> </ul>	<ul> <li>Free or low cost health services through managed health care plans</li> </ul>
Common- wealth Choice	<ul> <li>Unsubsidized health care coverage</li> <li>Choice of private health insurance plans</li> </ul>	<ul><li>Moderate to high income</li><li>Uninsured</li></ul>	<ul> <li>19 years or older</li> <li>Ineligible for Commonwealth Care</li> <li>Premium dependent on plan</li> <li>Income above 300% of FPL</li> <li>No income/asset limit</li> </ul>	<ul> <li>Access to standardized private health insurance plans</li> </ul>
Mass. Insurance Partnership	Massachusetts program that helps small business owners provide health insurance for their uninsured employees	<ul> <li>Small business owners</li> <li>Uninsured employees of small businesses</li> <li>Self-employed workers</li> </ul>	<ul> <li>Employers: must not have more than 50 employees; offer comprehensive health insurance to employees; pay 50% or more of employee costs; have one or more eligible employee</li> <li>Employees: must be between ages 19 and 64; be legal residents of state; be uninsured; meet income limits; and work for qualified employer</li> </ul>	<ul> <li>Up to 50% of employer's cost</li> <li>Up to % of employee's premiums based on affordability of employee</li> </ul>

What makes MassHealth a promising practice is its overall program quality and expansion of health insurance coverage to more than 90 percent of the population, as well as partnerships with local insurers, efficient information technology, and a small business tax incentive program. A study by the University of Massachusetts Center for Health Policy and Research (2007) found that MassHealth achieved quality ratings comparable to the top 25 percent of Medicaid plans in the United States (Massachusetts Center for Health Policy and Research, 2007). The system also uses Internet technology and collaborative relationships with insurers, including Boston Medical Center HealthNet Plan, Fallon Community Health Plan, Neighborhood Health Plan and Network Health, as well as community-based agencies and employers. MassQES (MassHealth Quality Exchange) is the state's secure Internet portal for submission of acute care hospital performance measures, which is part of its Pay for Performance Initiative. Commonwealth Connector, another Internet portal, allows residents to identify health insurance plans based on specific eligibility requirements and register for coverage online. The MassHealth Insurance Partnership provides small businesses with less than 50 employees an incentive payment to offset the employer's contribution to employer-based health insurance. The insurance partnership gives employers \$400 per year for individual coverage, \$800 for couples coverage, \$800 for one adult with one child and \$1,000 for family coverage (Commonwealth of Massachusetts, 2008). Massachusetts' CommonHealth, a program that serves low income residents and people with disabilities in the state, reported a participant pre-enrollment employment rate of 36 percent, which improved to 86 percent after one year of participation in the program. Monthly earnings increased from \$235 to \$634, and monthly hours jumped from 28 to 70 just 12 months after enrollment (Massachusetts Health Council, 2006).

# **5.6 Corporate Efforts**

We identified little in the way of innovative approaches by companies designed to ensure that health care coverage is affordable and meets the needs of people with disabilities. Large companies such as Microsoft Corporation and Google do offer short- and long-term disability leave policies, extensive health and wellness programs, 24-hour health hotlines and mental health counseling services. In addition, large retailers such as Walmart, Best Buy and Kay Jewelers offer low-wage semi-skilled jobs and the provision of comprehensive health insurance benefits to workers with disabilities. Walmart "associates" with disabilities may participate in a \$4 generic prescription pharmaceutical program and an Associate Resource Group that seeks to maintain diversity best practices among its labor force. Walmart also contributes a percentage of profits to charitable organizations that support people with disabilities.<sup>30</sup>

# 5.6.1 Comprehensive Mental Health Care

Several large companies provide extensive mental health coverage that has led to improvements in worker productivity and decreases in health care costs. Driven largely by the Mental Health Parity Act (MHPA) of 1996, which requires that annual or lifetime dollar limits on mental health benefits be no lower than spending limits for medical and surgical benefits, several large companies have used comprehensive mental health coverage as a way to increase productivity and save on health care costs.

For example, Delta Airlines, Eli Lily (Pharmaceuticals), First Chicago Bank, and Motorola all offer comprehensive physical *and* mental health insurance coverage to their employees with no preexisting

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<sup>&</sup>lt;sup>30</sup> Several other national retailers (e.g., Target) and some hotel chains (e.g., Marriot Corporation) also recruit and hire people with disabilities for semi-skilled positions.

condition policies. These companies also offer wellness programs, onsite psychiatric care, rapid response teams for crisis intervention, incentives for employee participation in preventive health care programs, supervisor training to help detect mental health problems among staff members, and opportunities for employees to be part of the health insurance acquisition process by helping to select provider networks. These companies subsidize initial mental health counseling visits and place limits on extended coverage. The costs of these services are offset by a company-wide cost-sharing program that reduces fees when utilization rates remain at a predetermined level (Robinson, Chimeto, Bush, & Papay, 2001). Both Fannie Mae and Motorola also offer comprehensive wellness programs that include onsite counseling and employee advocacy through their health insurance program, while Motorola surveys employees to determine the kinds of health insurance coverage that would be most beneficial to employees and their families.

# 6.0 Summary and Recommendations for Future Research

The American health care system is a labyrinth of federal and state policies, a free market economy, and labor market dynamics that relegate most people with disabilities to the secondary labor market where employer-based health insurance coverage is often unavailable or unaffordable. The success of future health care reforms in improving access to health care for people with disabilities may depend on how employers capture the benefits of accommodating qualified workers with disabilities (Baldwin & Johnson, 1992; Blanck et al., 2007). This calculus must address the rising costs of health insurance coverage and the potentially elevated cost of insuring people with disabilities relative to employees without disabilities as factors that influence the employment rate and occupational segregation of the labor market (Hill, Livermore, & Houtenville, 2003). A disability health care policy that reduces costs and resolves the social-structural barriers that create occupational segregation is likely to expand access to health care to more employed and uninsured people with disabilities.

This research review summarized three system-level barriers to access to health care for people with disabilities – disincentives of subsidized health care, labor market dynamics, and concentration of the health insurance market – and presented a bio-psycho-social model including several treatment-level factors that inhibit access to health insurance coverage and successful labor market reentry. It is the combination of these system- and treatment-level factors (or covariates) that limits access to the primary labor market and as a result, access to health care, for people with disabilities.

In the following sections we provide suggestions for future research on access to health care for people with disabilities, focusing on analytical methodologies that may improve access to health care for people with disabilities.

#### 6.1 Theoretical and Conceptual Mapping

As stated by Krause et al. (2001), "The entire return-to-work field is under-theorized." Of primary concern is the limited attention among researchers who study people with disabilities to the importance of theoretical and conceptual models that underlie methodological decisions, as well as the selection of covariates and analytical procedures for disability employment research. In this research review we presented a model that illustrates the dynamics of the return-to-work process as well as one that describes the problem of labor market segmentation and how it may impact access to health care for people with disabilities. These theoretically based models should be thoroughly tested to determine the relative strength of each underlying covariate. Establishing and testing theoretical and conceptual models is an essential step in the process of moving the state of the science forward in the area of disability employment and access to health care.

From a methodological point of view, the predictive analytical techniques used by disability employment researchers should be developed on a foundation of multivariate exploratory models, using factor or principle component analyses to explain and simplify the relationships among multiple covariates and to develop a better understanding of the underlying constructs that can later be incorporated into predictive models. By developing factors (constructs) comprised of multiple covariates, exploratory models and their constructs can be incorporated into predictive analytical models to design more comprehensive analyses of disability employment outcomes. Predictive analytics are useful only if the constructs underlying them are theoretically and empirically grounded and include independent variables that maximize the amount of variance explained by statistical models. Because there is little in the way of theory in the empirical disability employment literature and the same independent variables are often duplicated unnecessarily, we recommend exploratory techniques to create factors (or groups of variables that are highly correlated) for inclusion in predictive models to better explain why some people with disabilities are more likely to return to work than others.

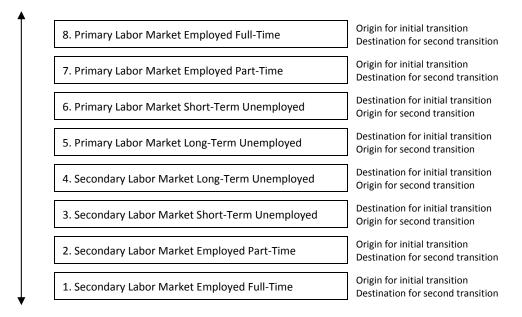
As stated above, access to health care for people with disabilities is largely a function of labor market position. People with disabilities employed in the primary labor market are more likely to have access to health care than those whose skills and training prepare them for secondary labor market jobs. The latter also have a greater incentive to rely on public health subsidized programs rather than return to work, whereas primary labor market workers have an incentive to return to work due to the greater likelihood of employer-based health insurance coverage being both available and affordable. In order to accurately model the return-to-work process, an analysis would have to include both treatment- and system-level variables. For example, (1) human-capital characteristics; (2) depreciation of human-capital; (3) eligibility and participation in subsidized public health programs; (4) demographic characteristics (i.e., race, gender, socioeconomic status, age, income, education); and (5) disability type and severity; (6) labor market position. System-level covariates would include (1) local unemployment rates; (2) industry unemployment rates; (3) HHI values; and (4) receipt of public subsidizes (i.e. SSI, SSDI). These must be included in a predictive model in order to accurately project the probability of people with disabilities returning to work, and to develop policies and programs that target people that have the potential to work but require additional supports.

To accurately account for the labor market position of study subjects, eight "states," referred to as origin, interim or origin/destination states should be used. This would allow respondents to transition out of one labor market position and into another by experiencing downward mobility, upward mobility and neutral transitions. Two years of Medical Expenditure Panel Survey Data would allow for six measurement intervals. Measurement Interval-Transition 1 (T1) would serve as the baseline measure when respondents voluntarily become unemployed due to the onset of a disability. Measurement Intervals-Transitions 2, 3 and 4 (T2, T3, T4) would capture the status of respondents at 6-month intervals after disability onset, while Measurement Interval 5-Transition 5 (T5) would capture the status of each respondent at 24 months after disability onset.

The labor market position of each respondent would be determined by the eight categories shown in the figure below. Labor market positions 7-8 and 1-2 are both origin and destination states because workers may experience downward or upward mobility after displacement and/or a long or short period of unemployment, by moving into the secondary or primary labor markets, respectively. In contrast, labor market states 6-7 and 3-4 function as destination states for the initial transition (T1) because workers must leave employment in order to transition to one of these (unemployment) states. However, during the second transition (T2), these become origin states. The conceptual model allows for eight change of state types for the transition out of workers' initial employed labor market position (T1:  ${}^{1}8\rightarrow6$ ,  ${}^{2}8\rightarrow5$ ,  ${}^{3}7\rightarrow6$ ,  ${}^{4}7\rightarrow5$ ,  ${}^{5}1\rightarrow3$ ,  ${}^{6}1\rightarrow4$ ,  ${}^{7}2\rightarrow3$ ,  ${}^{8}2\rightarrow4$ ) and 16 change of state types for the second

transition from unemployment to reemployment states (T2:  $(^{1}6\rightarrow 8, ^{2}6\rightarrow 7, ^{3}6\rightarrow 1, ^{4}6\rightarrow 2, ^{5}5\rightarrow 8, ^{6}5\rightarrow 7, ^{7}5\rightarrow 1, ^{8}5\rightarrow 2/^{9}4\rightarrow 8, ^{10}4\rightarrow 7, ^{11}4\rightarrow 1, ^{12}4-\rightarrow 2/^{13}3\rightarrow 8, ^{14}3\rightarrow 7, ^{15}3\rightarrow 1, ^{16}3\rightarrow 2).$ 

Figure 3. Transition and Origin "States"



Data from the Medical Expenditures Panel Survey's Household File includes employment and occupational characteristics, medical conditions and demographic characteristics. A medical provider file provides information about each respondent's medical condition. The unique case identifier DUPERSID, which is comprised of the respondent/person (PID) and dwelling numbers (DUID), would be used to merge MEPS files while the PANEL identifier would control for duplication of DUPERSID (panel respondents) across intra-annual data collections to avoid within panel duplication of respondents. These filtering criteria ensure that only one MEPS record per respondent is included in the final analysis.

## **6.2 Simulated Computation of Program Effects**

Generally, research on access to health care for individuals with disabilities is limited to descriptive information provided by states as they design and implement innovative Medicaid Buy-in and related programs. In the early 1980s, the SSA began conducting experimental research on the return-to-work outcomes of SSDI beneficiaries. In the 1990s, welfare demonstration programs expanded on work disincentive research using proportional hazards (Semi-Markov) models which measure the simultaneous effects of different covariates (independent variables) on decisions to return to work, while qualitative researchers identified physical, psychological and social factors that influence return-to-work outcomes (Krause et al., 2001).

Because of the complexity of this line of research, future research should focus on simulated outcomes to assess the value of programs that attempt to improve labor market access and expand access to health care among various subgroups of people with disabilities. This could be accomplished by holding constant and isolating certain variables that influence program effects, using a classification matrix to produce profiles of people with disabilities and simulating program conditions.

Access to health care is related to the career trajectory and job allocation of people with disabilities, which does not prepare those with long-term chronic disabling conditions for the primary labor market.

Changing this situation will require further exploration into the interpersonal, health care, health status, and employment prospects of workers with disabilities to better understand the interaction effects of labor market position, human capital credentials, demographic and socioeconomic characteristics, type of disability, and disability severity on labor market attachment and reattachment. Although we know that socioeconomic status plays an important role in this process, it is unclear how different kinds of disabilities and their severity influence employability and motivation to work. A classification matrix that articulates a number of "disability profiles" based on several characteristics, not unlike the existing disability severity (or impairment) scales, although considerably more detailed, should be used to take into consideration the extensive diversity among people with disabilities.

For example, at the most basic level, disabilities are caused by biological or environmental circumstances and may occur at any stage of the life-cycle (i.e., early childhood, childhood, adolescence, youth, adulthood, etc). The life-cycle stage during which the disability occurs is extremely important as it indicates at which developmental stage the human capital development process was inhibited by the onset of a disability. The severity of the disability (or degree of impairment), the type of disability, and whether it is acute or chronic, must also be added to the matrix, along with relevant demographic and socioeconomic characteristics. People whose disabilities began in childhood have different probabilities for economic, occupational and social mobility than those whose disabilities began in middle-age because for the latter, primary labor market human capital credentials and work experience may have already been in place at disability onset.

Drawing on multiple data sources, simulations of program effects (i.e., varying the availability of health care services, changing the amount of subsidies) can be designed to assess various scenarios related to access to health care for people with disabilities. As we discussed in Figure 1, an approach that incorporates variables from each component of the bio-psycho-social model should be used in future simulation-based methods to support the computation of expected program effects, including: employment status; subsidy value; disability severity; family/social support; social norms and expectations; regulatory context; state of the economy; occupational outlook; labor market conditions; stakeholder collaboration; subsidized health care disincentives; and health insurance market share concentration. Loprest and Maag's (2003) study provided a thorough analysis of disability onset and its association with high school completion and employment. But, it did not take into account the workplace environment, psychological factors and the severity of disability and its limitations. In some instances, application of a comprehensive classification matrix may require additional data collection and/or modification of existing national data collection initiatives.

Future research must take into consideration the diversity among people with disabilities so that findings can be used to identify the predictors of a range of disabilities, such as workers with traumatic brain injuries, spinal-cord injuries, vision and/or hearing impairments, and/or people with multiple disabilities, on return-to-work and access to health care outcomes.

## 6.3 Attitudes of People with Disabilities

Another important gap in research on access to health care is the perceptions of the needs of individuals with disabilities (Putnam et al., 2003; Schur et al., 2005). We did not identify *any* research studies that asked people with disabilities what they thought of the public health care subsidy programs, although we did find chat rooms, listservs and Web sites with informal discussions on the availability and quality of health care. A broader understanding of the cultural relevance of the accommodations being provided needs to be fully understood, as well as the role of health and wellness programs and alternative medicines and therapies that not only address secondary conditions, but also address the emotional needs of those with disabling conditions. For return-to-work research to usefully inform

government policy and the design of effective occupational rehabilitation service delivery system, there are a number of issues that need to be addressed by those funding or leading research programs in the area of return-to-work following injury.

# 6.4 Understanding Medical Professionals

Research on the training, attitudes, and treatment approaches of medical professionals, from all disciplines, should be conducted to evaluate how physician-employer-worker partnerships influence return-to-work outcomes and access to health care.<sup>31</sup> Another study should focus on workplace return-to-work and health care interventions that target people with disabilities through accessible workspaces, health and wellness programs, and disability onset.

# 6.5 Understanding Employers

Employers play a crucial role in recruitment and outreach to people with disabilities. They also play an important role in the return-to-work process. A survey, combined with qualitative field research, should be used to identify employers' disability management protocols, workplace accessibility and workplace dynamics to determine how well employers meet the needs of people with disabilities. This study could control for industry, occupational levels (i.e., primary/secondary) and/or size to determine which employers are positioned to support the return-to-work process, offer affordable health care to people with disabilities and maintain a work environment that is supportive of workers with disabilities.

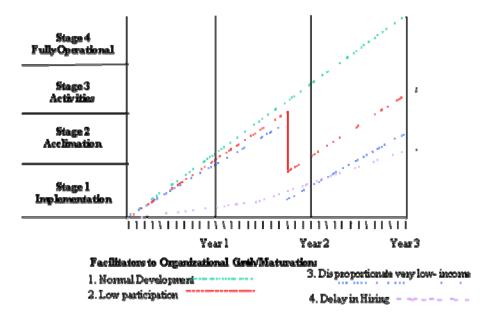
### 6.6 Research on Medicaid Buy-in Programs

Further empirical research on the Medicaid Buy-in programs should seek to estimate the programs' impact on employment using a comparison group framework in order to assess earnings and employment history while incorporating elements of the bio-psycho-social model. In addition, research should focus on the impact of program design and implementation procedures across the states. A cross-state comparison of the design features of each program and program outcomes would be beneficial as it would facilitate the replication of promising approaches to the Medicaid Buy-in program.

Because the Medicaid Buy-in programs began at different times, it would be helpful to retrospectively track their growth/maturation based on a comprehensive set of program implementation and outcome indicators. In Figure 3 we present a sample growth/maturation model that illustrates an organizational growth timeline. This illustration indicates that low participation rates, disproportionate representation of very low income families, and administrative hiring delays limited the growth/development of programs and "stunted" project implementation and the achievement of outcomes. Figure 3 also shows the approximate impact of these "inhibitors" on program development. These developmental milestones should be used to measure the effectiveness of Medicaid Buy-in programs by providing benchmarks for the amount of time it takes for a program to pass through the developmental stages of the framework. Ultimately, this approach will result in a growth/maturation typology that describes how Medicaid Buy-in programs develop over time, the implementation obstacles/inhibitors that impede implementation and the factors (facilitators) that facilitate program growth.

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<sup>&</sup>lt;sup>31</sup> We understand that ODEP is currently working with HHS/OD to develop a training curriculum for medical professionals.



**Figure 4: Growth/Maturation Framework** 

Research in the areas of disability employment and access to health care for people with disabilities is limited in scope and methodological rigor and in need of a widely accepted classification matrix that categorizes disabilities by type and severity and takes into consideration demographic, employment, occupational and psychological factors. As we move forward to the next phase of this project, which is the design of research methodology options for studies on access to health care and health and wellness, we will design such a classification system and a methodology for modeling disability outcomes based on the bio-psycho-social model. This research review lays the groundwork for the next task. We look forward to supporting ODEP in furthering its mission to improve the employment prospects of people with disabilities.

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# Appendix A: Research Review Methodology

The purpose of this document is to provide an outline of the approach that was used to develop the research review for the Health and Wellness Project. This document has two sections. Section I presents the goals of the literature review and describes our approach. Section II describes the purpose of and methodology for the meta-analyses.

### Section I. Research Review Strategy

The goals of the research review are to:

- Identify research and technical documents on cost effectiveness, productivity, and access to existing publicly and privately funded health programs.
- Identify research articles and papers that are appropriate for meta-analyses.
- Utilize information and data to propose research design options to examine access to public health care for people with disabling or potentially disabling conditions.
- Support research translation and knowledge transfer activities.
- Support the development of two white papers.

The areas to be covered in the research review are governed by the research questions proposed in the Statement of Work and those being developed during the literature review and subsequently approved by ODEP. These include:

- What is the composition of the population of individuals with disabilities in the labor market (hired with disabilities, disabled on the job, unemployed seeking work)?
- What is their insurance coverage status?
- What is the history of insurance for Americans with disabilities?
- What insurance options are currently available for Americans with disabilities (federal programs, state programs, employer-based private insurance, individual policies)?
- How do providers of insurance for individuals with disabilities differ in terms of their definitions of disability, eligibility criteria, and benefits offered?
- What are the trade-offs individuals with disabilities must weigh in negotiating the maze of health care options?
- What efforts have been made to address the disincentives inherent in some benefit programs (e.g., income restrictions)?
- What programs/policies/supports would, if available, prolong labor force participation/delay disability program participation among workers with disabilities?
- How can we assure access to adequate health insurance for people with potentially disabling conditions who do not qualify for employer-based group coverage so that they can remain in the workforce?
- What types of interventions could be undertaken earlier in the disability onset process to prevent/delay labor force withdrawal and how might such interventions be financed?
- What measures could be used to assess impact?

### **General Approach**

Our approach for the review was to first conduct a broad scan of the available literature on the specific topics (i.e., corporate wellness programs and access to health care) and then narrow the focus first to literature related to individuals with disabilities and then to the individual research questions listed above. In order to be all inclusive, our search included materials (peer-reviewed and unpublished reports, technical papers/documents and curriculum/textbooks) on the topic that date back to 1998. In addition to locating articles using standard electronic databases, we also searched organizations' websites and contacted key researchers/people who do work in this area. All material has been carefully catalogued and will be referenced in the final report. We would like to point out that a separate search was conducted for each research question so that the issues related to each were thoroughly researched to be described in detail in the final research review.

We searched for specific terms and identified prominent researchers in order to capture information related to our topics and subtopics. We documented our findings from each term, phrase and keyword used while searching each source, so that the search was not repeated. This information was shared with the study team so that staff could comment on their searches and make recommendations for additional search criteria. This efficient process ensures that the research review is defensible to reviewers. In preparation for the literature search process, we outlined the following parameters:

#### Appropriate Time Frame of Literature Search

Most of the literature was limited to the last 10 years because we wanted to focus on the current situation in a constantly changing environment (e.g., changes in ADA taking effect on January 1, 2009).

### Relevance of Literature

Brainstorming on the questions first posed in the Statement of Work, project staff identified the primary arenas for exploration and began to formulate both mediating questions (e.g., "What are progressive corporations doing to address the health care access needs of employees with disabilities?) and additional research questions (e.g., "What are the health care access disincentives that affect the recruitment and retention of workers with disabilities?"). During the initial search, we separated the documents into typological groups (e.g., commentary, policy, research, etc.) for review for relevance, methodology, key findings, and limitations. We also sorted by methodology, quantitative and qualitative, and subcategories, quantitative-interventional and qualitative-interventional.

# Writing the Review

Using a reporting matrix with details of the literature search, staff reviewed the articles, books, Web sites, and other sources identified, recording the reference, summary, findings, and gaps. This matrix documented what was found and formed the foundation of the final review. A sample of the matrix is presented below.

Reference (APA 5)	Туре	Abstract	Outcomes	Limitations	Retrieval information
Caruk, N., Chabot, C., Melmed, R., Rivera, C., and Barr- Saxena, A. The Challenges of Living with Disabilities in Connecticut	Presentation	The UCONN Master of Public Health Program's Practicum Project is a supervised service-learning experience that integrates curriculum with hands-on experience in a public health setting. All 2nd year students are expected to work collaboratively in assessing the extent, causes and public health responses to a selected public health problem confronting citizens of Connecticut. The focal topic for the 2007 Project was The Challenges of Living with Disabilities in Connecticut. During this past spring, 17 students of our program, working alongside 50 community- based stakeholders across Connecticut, completed 1,800 hours of service-learning.	Inventory: Definitions of disability from a variety of stakeholders; estimated numbers of persons living with disabilities in Connecticut; range of their disabling conditions; services in place to facilitate the full integration of persons with disabilities	Unpublished	http://digitalcommons.uconn.edu/cgi/viewcontent.cgi?article=1001&context=uchcgs_presentations

#### **Search Terms**

To facilitate the initial search, we developed a list of terms to pursue. These included: Individuals with disabilities and/or:

- health care
- health care access
- health care affordability
- health insurance
- health insurance access
- · health insurance affordability
- employed and health care
- employed and health care access

- employed and health care affordability
- employed and health insurance
- employed *and* health insurance benefits
- employed *and* health insurance affordability
- unemployed and health care
- unemployed *and* health care access
- unemployed and health care affordability
- unemployed and health insurance
- unemployed *and* health insurance benefits
- unemployed *and* health insurance affordability
- employed *and* federal benefit programs
- employed and state benefit programs
- remaining in labor force
- leaving labor force
- special needs
- mental health

# Electronic Database Search Engines

What follows is the core list of electronic databases that were searched across topics.

- BioMed Central.
- CINAHL.
- EconLit.
- JSTOR.
- JSTOR-economics.
- PAIS International.
- PubMed.

# **Related Organizations and Web Sites**

Agency for Healthcare Research and Quality	http://www.ahrq.gov/	
American Public Health Association	http://www.apha.org/	
Burton Blatt Institute	http://bbi.syr.edu/	
Centers for Disease Control and Prevention	http://www.cdc.gov/	
Centers for Medicare and Medicaid Services	http://www.cms.hhs.gov/	
Consortium for Citizens with Disabilities	http://www.c-c-d.org/	
Centers for Workers with Disabilities	http://cwd.aphsa.org/Home/home_news.asp	
The Employee Benefit Research Institute (EBRI)	http://www.ebri.org/	

The Employee Benefits Security Administration	http://www.dol.gov/ebsa/	
(internal to DOL)		
Health Management Research Center	http://www.hmrc.umich.edu/	
Interagency Committee on Disability Research	http://www.ICDR.US	
	http://www.icdr.us/proceedings.html	
International Monetary Fund	http://www.imf.org/external/index.htm	
Internal Revenue Service	http://www.irs.gov/	
The Henry J. Kaiser Family Foundation Annual	http://www.kff.org/insurance/7790/	
Employee Health Benefits Survey		
Mathematica	http://www.mathematica-mpr.com/disability/#Reports	
National Center for the Dissemination of Disability	http://www.ncddr.org/	
Research		
National Center on Physical Activity and	http://www.ncpad.org/	
Disability Health Promotion		
Pennsylvania Association for Individuals with	http://www.paid-online.org/	
Disabilities		
Rehabilitation Research and Training	http://www.ilr.cornell.edu/edi/p-eprrtc.cfm	
Employment Policies for Persons with		
Disabilities (Cornell University)		
Social Security Administration	http://www.ssa.gov/	
Urban Institute	http://www.urban.org/	
U.S. Department of Health and Human Services	http://www.hhs.gov/	
U.S. Department of Labor	http://www.dol.gov/	
Virginia Commonwealth University's Benefits	http://www.vcu-barc.org/	
Assistance Resource Center		
World Health Organization	http://www.who.int/en/	

# **Relevant Journals**

American Journal of Health Promotion		
Applied HRM Research		
Disability and Health Journal		
Disability and Rehabilitation		
Disease Management and Health Incomes		
Family and Community Health		
Health and Social Care in the Community		
Health Education Research		
Industrial Relations		
Journal of Occupational and Environmental Medicine		
Journal of Rehabilitation		
Mental Retardation and Developmental Disabilities Research Reviews		
Occupational Medicine		
Preventive Medicine		

#### **Books**

Rimmer, J.H., Riley, B., Want, E., and Rauworth, A. (2005). *Accessibility of Health Clubs for People with Mobility Disabilities and Visual Impairments*. Washington, DC: American Public Health Association.

Spechler, J.W. (1996). Reasonable Accommodation: Profitable Compliance with the Americans with *Disabilities Act.* Delray Beach, FL: St. Lucie Press.

Blanck, P, Hill, E., Siegal, C., and Waterstone, M. (2009 2<sup>nd</sup> edition, forthcoming). *Disability Civil Rights Law and Policy: Cases and Materials*, Minnesota, MN: Thomson/West Publishers.

# **Appendix B: Research Questions**

Most of the research questions that directed this review of the literature were derived from research presentations at the *Strengthening the Intersection of Demand-side and Supply-side Disability Employment Research: Toward a Coordinated Federal Research Agenda* conference in June, 2008, hosted by the Interagency Committee on Disability Research (ICDR) Interagency Subcommittee on Employment (ISE). The conference involved "a broadly ranging discussion among experts in the business and disability communities on the nexus of demand-side and supply-side research..." and recommended research the ISE could use to "establish a blueprint for a five-year interagency research agenda." Reinforcing their recommendations, as evidenced by this review of the literature, there are significant gaps in our research on these critical issues.

The table below links the research questions with the narrative by section and page and with annotations on the gaps we identified.

Research Question	Location	Comments
Disincentives  1. What are the health care access disincentives that affect the recruitment and retention of workers with disabilities?	Section 1.2 (6) Section 4.0 (14) Section 4.1 (14) Section 5.5 (26)	
1.1 What programs have been put in place to address these disincentives?	<b>Section 1.2</b> (6)	
1.2 What gaps remain in existing programs and policies that disincentivize transitions to work and reemployment for people with disabilities?	<b>Section 1.2</b> (6)	
What kinds of programs, policies and support services prolong labor force participation or delay disability program participation among workers with disabilities?	<b>Section 1.2</b> (6)	
2.1 What are the attitudes of people with disabilities in the workforce regarding the kinds of programs that would support or prolong their labor force participation?		We found no research on attitudes of individuals with disabilities on the kinds of programs that would support or prolong their labor force participation. This may be an area of expansion for this project.
2.2 What research has been conducted on health care access that prolongs labor force participation?		We found no research on health care access that prolongs labor force participation. This may be an area of expansion for this project.TTW and other employment programs are promising, but to date, have not proven to be effective in prolonging labor force participation.
2.3 What are "forward-thinking corporations" doing to address barriers to health care for employees with disabilities?	<b>Section 5.6</b> (29)	There are a few large corporations that have focused on their general employee population. With the exception of large retailers that hire people with disabilities into low to moderate wage jobs, we did not identify corporations that focus on workers with disabilities.

2.3.1 How effective are these programs in terms of their impact on health care costs and reductions in employment interruptions among people with disabilities?	Section 5.6 (29)	The impact of these programs is unclear. There is quasi-experimental research that indicates that reductions in employment interruptions and increased productivity may result from corporate initiatives designed to improve health care access through health and wellness programs. But this research is limited and scope and methodological rigor.
3. What types of interventions could be undertaken earlier in the disability onset process to prevent/delay labor force withdrawal and how might such interventions be financed?  6. The process to prevent/delay labor force withdrawal and how might such interventions be financed?		We found no research on interventions to prevent or delay labor force withdrawal. This may be an area for expansion of this project. We would recommend a comprehensive approach that begins with TTW and adds counseling, professional development, workplace accommodations training for employers and stronger regulatory oversight of the recruitment and hiring process. There is evidence that people with disabilities are subject to prejudice and discrimination against throughout the hiring process, which continues once they are hired.
3.1 To what extent does the type and severity of a disability prevent/delay labor force withdrawal?	Section 1.2 (6) Section 6.2 (36)	Disability type and severity are key factors in delaying withdrawal and facilitating labor market reentry.  Because of the limitations of the existing research on disability type and severity, we are unable at this time to provide empirical evidence across a range of disability and types and severity. In section 6.2 we provide a summary of a simulated computation of program effects that can be used to develop a stronger research base in this area.
3.2 How should interventions be customized to support different levels of disability severity?		We found no research on customization of interventions to prevent or delay labor force withdrawal. This may be an area for expansion of this project. Disability severity (and type) complicates the research process. As a result, there is limited empirical information on interventions that support different levels of severity and their outcomes.

3.3 What are the cost differences for interventions that may prevent/delay labor force withdrawal by type and severity of disability?		We found no research on costs for interventions to prevent or delay labor force withdrawal. This may be an area for expansion of this project. Some research exists on state funded programs. But the cost-effectiveness of programs that prevent/delay labor force withdrawal and take into consideration disability type and severity, is unavailable. Most programs focus on one kind of disability and a certain level of disability severity. This fact further complicates research in this area.	
4 What measures could be used to assess impact?	<b>Section 1.2</b> (6)	Time in labor force after disability onset by disability severity and age of onset.	
Employer-based Group Coverage  5 How can access to adequate health insurance be assured for people with potentially disabling conditions, who do not qualify for employer-based group coverage, so that they can remain in the workforce?	Section 5.3 (25) Section 5.4 (26)	With the exception of COBRA, we found no research on access to health insurance for people with potentially disabling conditions who do not qualify for employer-based group coverage, so that they can remain in the workforce. This may be an area for expansion of this project. Promising practices, such as reinsurance programs and community-based financing are programs that	
5.1 What health care options exist for individuals with potentially disabling conditions, who do not qualify for employer-based group coverage, so that they can remain in the workforce?			
5.2 What are/should be the options for individuals with potentially disabling conditions who do not qualify for employer-based group coverage so that they can remain in the workforce?		should appear to expand access to health care. Additional research is needed to determine if these programs are cost-effective and sustainable.	
5.3 What are the cost-to-benefits of these programs?			
Best Practices  6. How will employers utilize best practices and lessons learned to develop and enhance employee access to health care?		The ODEP employer survey provides information on how workplace accommodations are used by employers.	
6.1 What promising or best practices are currently being used by employers to develop and enhance access to health care for employees with disabilities?	Section 5.0 (24)		
Collaboration	Section 5.0 (24)		
7. What can be done to encourage the most effective working relationships between employers, home and community-based social service providers and primary care organizations?			
7.1 What existing employer/health care/provider networks have had success in developing effective working relationships?	Section 5.0 (24)		
7.2 What are the characteristics of these programs?	Section 5.0 (24)		

7.3 What are the measures which determine value added employment and health service partnerships?	Section 5.0-5.6 (24-30)	Measures that determine value added employment and health service partnerships through reinsurance and community-based financing initiatives include: patient satisfaction, quality of care, reductions in health insurance premiums and hospital fees. Additional research is needed to on health care partnerships to determine how they impact the health and well-being of people with disabilities.
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