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Funding Options for Personal Assistance Services

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Executive Summary

This white paper is a required deliverable under Task Order DOLU089428185 (Flexible Spending Account Personal Assistance Services Study, commissioned by the Office of Disability Employment Policy (ODEP) of the Department of Labor. It examines the potential involved in the creation of a Flexible Spending Account for Personal Assistance Services. Personal assistance services (PAS) refer to "formal and informal help provided to people with disabilities to assist them in tasks essential for daily living" (Harington, Newcomer, LaPlante, Kaye, Stoddard et al., 2004, pp. 2). The establishment of a Flexible Spending Account (FSA) for the Personal Assistance Services (PAS) represents another step in the direction of reducing obstacles to participation in the workforce for people with disabilities, as it reduces the cost associated with paying for the services of a personal assistant. PAS are necessary for more than one half of people with at least one activity of daily living (ADL) need (Nosek, 2002). Many individuals, who receive state support for PAS while in school, are unable to obtain employment that allows them to cover their PAS costs once in the labor market (Nosek, 1999). With one fourth of the population that is not working full time citing the need for PAS as a reason for their part-time or lack of participation in the work force, this account may render employment more affordable than it currently is for individuals with PAS needs.

Disability has been conceptualized differently over time. The medical model of disability is the most prevalent, defining disability in terms of physical and mental impairments. Due to specific diagnostic criteria also determining eligibility for government programs and other benefits (Jurkowski, 2007), it remains the prevailing model to frame perceptions of disability. This framing of disability means many services for persons with disabilities foster dependence rather than independence (Clark, 1998) and disenfranchises a large part of the population (Caplan, 1998). Years of activism, the move towards de-institutionalization and independent living and the passage of the Americans with Disabilities Act of 1990 have promoted a paradigmatic change in the perceptions of disabilitiy. Still, there are many hurdles in the way of allowing people with disabilities to live independently and as full members of their community. Among the most critical are the difficulties associated with obtaining and retaining employment that provides the autonomy disability advocates envision.

Employment rate for persons with disabilities is 38.5 percent as opposed to the 83.7 percent of their counterparts without disabilities (Bureau of Labor Statistics, 2009). Even when they are employed, the mean income for a family with at least one person with disabilities is only 71.8 percent of the income of families without anyone with a disability. Lower income levels coupled with higher costs related to living and working independently, such as location, accommodations, the need for personal assistance services (PAS) and any other equipment that may be needed to facilitate independent living, the high out-of-pocket costs associated with their health care needs (Mitra, Findley, & Samboorthi, 2008/2009) all offer explanations as to why up to 80 percent of households with one person with a disability have zero or negative assets (Morris, 2004). Encouraging people with disabilities to work and build assets is in line with the goal of the independent living movement. Reducing the cost associated with working for individuals with PAS needs represents a positive step towards promoting work and asset accumulation for individuals with disabilities. An FSA allows persons with disabilities to put aside pre-tax money to pay for their PAS, reducing their overall tax burden and allowing for more discretionary income after those services are paid for each month and potential long-term asset building.

This study used as primary research methods a combination of qualitative methods that included a thorough survey of the literature on personal assistance services and the history and development of

flexible spending accounts as part of employee benefits. We conducted a series of stakeholder interviews, allowing the collection of the perceptions not only of members of the disability community but also of human resources experts with vast experience dealing with flexible spending accounts. These interviews illuminated several aspects involved in the implementation of a new type of account and the impact such a benefit would have on individuals with disabilities. The study also included a quantitative analysis using data from the Medical Expenditure survey to assess the impact of rising disposable income on return to work decisions of people with disabilities. Finally, we received feedback on this study from a group of individuals who play an important role in government and in the disability community. Their insights and suggestions were included in this report.

In order to better understand the use of flexible spending accounts as a public policy initiative and its potential as means for financing PAS, we researched the history and development of FSA's from inception to the present, highlighting the differences in the types of FSA's. In addition, we assessed the levels of participation by employers and employees in flexible spending accounts. The availability of FSA's has been shown to be more concentrated among larger firms, although several states have approved incentives for small business to offer them to employees. On the employee side, participation has been shown to be higher among employers in higher tax brackets as they expect to have larger tax savings. Still, because the sums involved in personal assistance services are high, the creation of PAS FSA brings potential high tax savings for all users.

This study identifies three main populations that would be directly affected by the creation of a PAS FSA: persons with disabilities needing non-medical PAS, family and friends or informal caregivers providing PAS services at no cost and non-medical paid PAS providers. Unpaid caregivers, of whom there were 44.4 million reported in 2004 (Feinberg, Newman, Gray, Kolb, & Fox-Grange, 2004), would be able to receive compensation for their services, increasing morale, and reducing stress. In some cases family and friend caregivers may be able to return to careers, or reduce their absenteeism in their current jobs because the ability to pay a non-medical provider to come in is available. Our analysis shows that persons able to access PAS reduced their medically related expenditures, could increase their retirement savings, develop assets, and afford to obtain services that increase their presence in the workforce and reduce their stress. Other groups directly involved in the creation of such accounts were also assessed, including the federal government, as a PAS FSA would encourage individuals to leave disability rolls but at the same time reduce certain tax revenues.

This study surveys other tax-benefitted programs in order to assess whether personal assistance services could be financed through existing mechanisms and how the savings afforded by an FSA compare against other types of tax breaks: Health Savings Accounts (HSAs), Impairment Related Work Expenses deductions (IRWE) and the existing dependent care FSAs. HSAs are medically related, and do not currently cover non-medical PAS services. In addition, people with disabilities have much higher health care expenses on average than people without disabilities. As a result, a change to include PAS funding in an HSA could deprive individuals with disabilities from the HSA benefits related to their health care. IRWEs are filed in one's annual tax return as a line in the itemized deductions form. For this reason, individuals have to choose between claiming PAS as an IRWE in the itemized form and claiming the standard deduction all taxpayers can take advantage of. In case one's PAS expenses in conjunction with other possible itemized deductions do not exceed the standard deduction, it is not worth using the itemized schedule. Conversely, if the expenses surpass the standard level, the tax benefit would only rise to the amount that exceeds the standard deduction. In practice, the tax reduction afforded by the IRWE would not include the full amount spent on PAS. Finally, a modification of existing dependent care FSAs to include personal care is considered. While this possibility would probably reach more individuals, as a large number of employers already offer dependent care FSA's, the limits on the account would have to

be lifted, otherwise PAS users with dependents would have to divide his pre-tax dollars to fund their own care and that of a dependent through that account. However, increasing the cap would be problematic, as the dependent care FSA is already very popular, and a cap increase would imply a significant income tax revenue loss for the federal government. We present a draft for legislation to create an FSA for PAS, based on the American with Disabilities Act of 1990, the Health Insurance Portability Act of 1996 and the IRS code.

This white paper discusses the Obama Administration initiatives for promoting the employment of individuals with disabilities. These initiatives include educating employers, supporting small businesses who hire workers with disabilities, promoting work flexibility, and supporting the Community Choice Act. In addition, we examine current Congressional initiatives regarding individuals with disabilities, especially those with PAS needs. We look at two existing legislative proposals: the Achieving Better Life Experiences Act (ABLE) of 2009 and the Community Living Assistance Services and Supports Act (CLASS) of 2009. These legislative initiatives align with the independent living movement, as they create new mechanisms to privately finance the very special needs of individuals with disabilities and insure workers' long-term care needs, respectively.

Finally, our research identified five potential challenges involved in the creation of a PAS FSA. First, pre-tax employee benefits cause disparities in the tax system. Second, the Treasury Department has concerns about the multiplication of pre-tax employee benefits may erode the tax base. Third, informal caregivers may not want to provide social security numbers for employment restricting the choice of care provider. Fourth, many employers do not offer FSAs, for a variety of reasons. Finally, participation is low for FSAs limiting its potential impact.

Introduction

The Office of Disability Employment Policy (ODEP) within the U.S. Department of Labor uses research and analysis to address employment challenges facing people with disabilities. The ODEP provides national leadership on the employment of people with disabilities by funding research and collaborating with other federal agencies and advocacy groups to develop and encourage the use of evidence-based employment policies and practices, and it provides reliable information on the employment of people with disabilities. This issue paper is a required deliverable under Task Order DOLU089428185 (Flexible Spending Account Personal Assistance Services Study). The paper focuses on personal assistance services (PAS), "Formal and informal help provided to people with disabilities to assist them in tasks essential for daily living" (Harrington, Newcomer, LaPlante, Kaye, Stoddard et al., 2004, p. 2).

In recent years, the term *personal assistance services* (PAS) has been used increasingly to replace *home and community-based long-term care*, reflecting the philosophy of the independent living movement[1]and de-medicalizing the services needed "to enable persons with disabilities to engage in any and all life activities that nondisabled persons normally pursue: going to school, going to work, socializing with friends, participating in sports, hobbies, and other recreational activities, and attending community functions" (U.S. Department of Health and Human Services, 2004).

In the sections that follow, we describe the need for PAS and introduce a payment mechanism that would enable individuals with disabilities to purchase some of these services with pre-tax dollars. In Section 1, we provide background on the need for PAS. In Section 2, we describe other pre-tax systems already in place that pay for qualified medical and dependent care needs. Sections 3 and 4, we outline specifics of the proposed PAS flexible spending account (FSA). In Section 5, we estimate the numbers and types of individuals who may be impacted by a PAS FSA. In Section 6, we discuss the potential impacts on each group. Section 7, using odds-ratios to simulate the effect of the pre-tax program, we describe the extent to which incentives to work may be offset by work disincentives.[2] We describe alternative tax-benefitted funding mechanisms for PAS in Section 8. In Section 9, we discuss possible next steps toward implementation. Finally, in Section 10 we summarize the key issues laid out in the paper. We derived the information presented here from a review of research studies and policy papers (both published and unpublished) and from interviews with key informants.

Section 1. Background

In 1968, "The notion that a large proportion of people with 'severe disabilities' could live independently in the homes and communities of their own choosing was, for the most part, wishful thinking" (Batavia, 1998, p. 2). This belief can be attributed, in part, to the widespread use of the medical model of disabilities "that defines disabling conditions as principally the products of physical and mental impairments that constrain performance" (Pope & Tarlov, 1991).

The medical model of disability[3] is one of three that have developed sequentially over time to define impairment and provide "a basis upon which government and society can devise strategies for meeting

[1] See DeJong as cited in Shreve (n.d.) for a history of the independent living movement.

[2] Odds-ratios provide information on the likelihood of an event occurring in one group compared to the likelihood of the same event occurring in another group.

[3] The medical model, based on scientific views and practice, is one in which "persons with disabilities assume the role of patient" (Seelman, 2004).

the needs of disabled people" (Connections for Community Leadership, 2005-2007). The others are the traditional model[4] and the social model.[5] In this paper, we refer to the medical model because it "still prevails within most of the legislative efforts since disease-specific diagnostic categories generally serve as eligibility criteria" (Jurkowski, 2007, p. 138).

On its "Models of Disability" page, the Connections for Community Leadership Web site (2005-2007) explains that

> Models reveal the ways in which our society provides or limits access to work, goods, services, economic influence, and political power for people with disabilities…. The Medical Model holds that disability results from an individual person's physical or mental limitations, and is largely unconnected to the social or geographical environments. It is sometimes referred to as the Biological-Inferiority or Functional-Limitation Model…. From this, it is easy to see how people with disabilities might become stigmatized as 'lacking' or 'abnormal'….
>
> The Medical Model places the source of the problem within a single impaired person, and concludes that solutions are found by focusing on the individual…. In simplest terms, the Medical Model assumes that the first step solution is to find a cure or—to use WHO terminology —make disabled people more 'normal.' This invariably fails because disabled people are not necessarily sick or cannot be improved by remedial treatment. The only remaining solution is to accept the 'abnormality' and provide the necessary care to support the 'incurable' impaired person. Policy makers are limited to a range of options based upon a program of rehabilitation, vocational training for employment, income maintenance programs and the provision of aids and equipment.

Influenced by historically broad acceptance of the medical model, health and social services programs have tended to foster dependence rather than personal autonomy (Clark, 1998). The programs categorize people with disabilities as permanently ill and incapable of meeting their own needs. Accordingly, these programs focus on individuals rather than society.

Disability rights groups point out that "treating chronic illness and disability strictly as medical problems 'disenfranchises' a large segment of society by making them permanent objects of social beneficence, a status that few if any members of our society would wish to occupy" (Caplan, 1988). Now, following decades of activism and building on the foundations of the civil rights, deinstitutionalization, self-help, de-medicalization, and consumerism movements (McDonald & Oxford, n.d.), perceptions of the competence and capability of people with disabilities have changed dramatically, and growing numbers of individuals with disabilities live independently in the community.

In spite of this progress, the 25,000,000 working-age people in the United States with sensory, physical, mental, or self-care disabilities are at a considerable disadvantage when compared with working-age people without disabilities (Houtenville, Erickson, & Lee, 2007). Working-age people with disabilities have an overall employment rate of 38.5 percent, compared with 83.7 percent for people

[4] "The traditional model is based on culturally and religiously determined knowledge, views, and practices… which place people with disabilities on a continuum from human to nonhuman" (Seelman, 2004). Seelman cited the egregious examples of cultures in which infants with disabilities are killed.

[5] The social model "makes a clear distinction between the impairment itself (such as a medical condition that makes a person unable to walk) and the disabling effects of society in relation to that impairment" (Michigan Disability Rights Coalition [MDRC], 2007)

without disabilities (U.S. Bureau of Labor Statistics, 2009).[6] According to the U.S. Census Bureau (2002), even when they work, the median income of families with at least one member with a disability was 71.8 percent of the median income of families without members with a disability (see Table 1). While 33 percent of American households have zero or negative assets, for people with disabilities estimates run as high as 80 percent (Morris, 2004).

Table 1. Median Family Income by Disability Type for Families Without and With at Least One Member with a Disability, 2000

Disability Status	Median Family Income
Without disability	$54,515
With any disability	$39,155 (71.8 percent)
With sensory disability	$38,775 (71.1 percent)
With physical disability	$36,950 (67.8 percent)
With mental disability	$36,197 (66.4 percent)

Note. From U.S. Census Bureau (2002)

The U.S. Census Bureau (2002) estimated that 18,100,000 non-institutionalized civilians age 5 to 64 years have a disability. According to Adams, Barnes, and Vickerie (2008), about *5*,800,000 working-age people (i.e., aged 18 to 64 years) in the United States have difficulty performing activities of daily living (ADLs) (e.g., dressing, bathing, or getting around inside the home) or instrumental activities of daily living (IADLs) (e.g., cooking or using the phone) (Adams et al., 2008). Although the total population estimate includes children (aged 5 to 17 years), these data suggest that working-age individuals who have difficulty performing ADLs and IADLs represent approximately one third of the population reported to have disabilities. These people need PAS to live independently in the community (Nosek, 1991).

The vast majority of people who need such services receive PAS from family members (83 percent), most often a spouse or daughter. According to the 1991/1992 Survey of Income and Program Participation (cited by Kennedy, LaPlante, & Kaye, 1997), only 9.2 percent of people who need PAS use paid direct-care providers as their primary source of assistance, although those who generally rely on unpaid PAS may pay for services when the unpaid provider is unavailable. LaPlante, Harrington, and Kang (2002) estimated that 3,200,000 people receive an average of 17.6 hours of paid help per week. According to the Paraprofessional Healthcare Institute (2008), the nominal median hourly wage for personal and home care aides increased 14 percent between 1999 and 2006, but the real median wage (adjusted for 1999 dollars) declined by 4 percent over the same period. Nominal median hourly wages within the contiguous United States in 2006 ranged from $6.41 in Texas to $10.78 in Massachusetts.[7] Using the average of 17.6 hours per week cited above (LaPlante et al., 2002), the average annual cost for personal assistance in the contiguous United States ranges from $5,866 in Texas to $9,866 in

[6] McNeil (2000) reported a disability employment rate of 47.3 percent for the 9,200,000 people with disabilities who do not participate in Social Security Disability Insurance (SSDI) or Medicare.

[7] The median nominal hourly wage in Alaska was $13.64 in 2006. In spite of its high cost of living, Hawaii records a median nominal hourly wage of $8.35, down from $8.81 in 1999.

Massachusetts.[8] Based on the disparity in median family income reflected in Table 1 for families with and without at least one member with a disability, any reduction in out-of-pocket expenses for PAS users would be beneficial.

Asset development is a strategy that shifts the emphasis of public policies that are only cash transfer programs to policies that encourage individuals and families to save money and make investments that increase in value over time, such as savings and retirement accounts, business and home ownership. The assumption is that as individuals develop assets, they and their families will be able to move out of poverty and remain out of poverty (Hoffman, 2006; Massachussets Asset Development Commission, n.d.). Asset accumulation provides individuals and families with numerous benefits, including protection against sudden income shortfalls. Being able to rely on accumulated assets helps individuals to bridge periods of financial stress, improving household stability (Hoffman, 2006; Massachussets Asset Development Commission, n.d.) In addition, by being able to rely on accumulated assets, individuals are better equipped to plan for the future, including investing in less tangible forms of assets such as educational achievement, job skills and training, access to credit, all of which exponentially raise one's prospects of being lifted out of poverty permanently.

Rehabilitation counselors frequently have clients who receive state agency support for their personal assistance needs while they are attending school, but are unable to secure employment at levels high enough to cover PAS expenses on their own (Nosek, 1990). Personal assistance services costs can run very high. The average annual cost for personal assistance services in the contiguous United States in 2006 ranged from $5,866 in Texas to $9,866 in Massachusetts, as the average number of PAS hours reached 17.6 hour per week (LaPlante et al. 2002). Many times the dependence on public programs to cover such costs reduces the employment potential of individuals with disabilities, as many states restrict the earning threshold for public benefit beneficiaries. Providing individuals with disabilities and PAS needs with affordable alternatives to finance their personal assistance services is central to any initiative to make these individuals independent members of the community.

The ability to save in order develop and build on tangible (such as home ownership) and intangible assets (such as higher education) on which one can rely on in tougher times is at the core of asset development strategies. This report evaluates the potential of such an asset development strategy: the creation of a new *flexible spending account* (FSA) to fund PAS. Such an account would allow individuals to use pre-tax income to cover their personal assistance expenses, in practice reducing the costs of such services as an account holder's tax burden is reduced. This initiative falls in line with asset development initiatives that aim at removing barriers to employment and asset accumulation for people with disabilities. By increasing the purchasing power of people with disabilities, this new PAS flexible spending account would not only make PAS more affordable, it would also produce substantial savings in the form of a reduced income tax burden. The tax burden reduction can be significant, as personal assistance services expenses can be quite substantial.

FSAs are pre-tax accounts that allow an employee to pay for certain health care, dependent care, and adoption costs not covered or not fully covered by other benefits. Currently, employers may offer three kinds of FSAs: health care, dependent care, and adoption. Each is described briefly here to provide background for the proposed PAS FSA. At the beginning of every employer's plan year, employees may designate portions of their salaries to cover allowable expected expenses. That amount is not counted as part of employees' taxable income, and a set amount (determined by the total amount designated

[8] The median annual cost for PAS in Alaska would be $12,483.

and the number of pay periods in the year) is deducted from each paycheck. There is no legal limit on the amount an employee may contribute to an FSA for health care, but each employer may set a limit (U.S. Department of the Treasury, Internal Revenue Service, 2008d). The dependent care FSA has an annual limit of $5,000 (U.S. Department of the Treasury, Internal Revenue Service, 2008a). The maximum amount of employer-provided adoption benefits that can be excluded from income is $11,650 (U.S. Department of the Treasury, Internal Revenue Service, 2008c). By law, unspent funds in FSAs at the end of the plan year revert to the employer (Employee Benefit Research Institute, 2008).[9] Health Care FSAs may be used to cover medical costs for employees or their dependents (U.S. Department of the Treasury, Internal Revenue Service, 2008a). Funds from dependent care FSAs may only be used for the care of dependents (U.S. Department of the Treasury, Internal Revenue Service, 2008a). Adoption FSAs cover adoption expenses for a child whose adoption has been finalized or for adoption efforts that were not successful (U.S. Department of the Treasury, Internal Revenue Service, 2008c).

Section 2. A Personal Assistance Services Flexible Spending Account for Persons with Disabilities

The proposed fourth type of FSA would cover the costs of PAS for workers with disabilities. As with other FSAs, individuals with disabilities could use pre-tax dollars to pay for the services, and as with existing FSAs, employers would determine whether to include a PAS FSA in their cafeteria plan of benefits. In addition, self-employed individuals also could set aside pre-tax dollars for PAS coverage.[10]

Employees who choose to utilize a PAS FSA would specify the amount of pre-tax money to be set aside and use those funds to pay for personal assistance. Those dollars would be deducted from the employee's annual salary through a pre-tax payroll deduction and would not be included as part of the employee's taxable income. The exclusion from taxable income is designed to reduce employees' concerns about losing public benefits they may be receiving.

The proposed PAS FSA would have a $15,000 cap. Employees would have complete flexibility to determine when, where, and by whom specific services would be provided. Excluding the employee's spouse or dependents, paid providers could include traditional agency direct-care workers, independent employees, and family or friends.[11]

People with disabilities must weigh the costs and benefits of employment. All else being equal, additional work-related expenses and the loss of public health-care benefits may mean that the costs of employment outweigh the advantages of employment (Livermore, Stapleton, Nowak, Wittenburg, & Eiseman, 2000). A program that enables individuals with disabilities to use pre-tax dollars to pay for PAS lowers their out-of-pocket expenses and the costs of entering the job market while it maximizes their independence. By addressing their needs, individuals with disabilities may be encouraged to enter or return to the labor market and to start paying caregivers who were previously uncompensated

[9] A 2005 ruling by the Internal Revenue Service allows employers to offer employees a grace period of up to 2 1/2 months after the end of the plan year to exhaust remaining funds in their expired FSAs (as cited by the Employee Benefit Research Institute, 2008, Chapter 48; U.S. Department. of the Treasury).

[10] Including self-employed individuals is not an unprecedented recommendation. The National Taxpayer Advocate (2008) suggestedthat Congress repeal IRC § 162(l)(4) to place self-employed taxpayers on an equal footing with their wage-earning counterparts so that the self-employed could exclude the amount of health insurance premiums from their gross income.

[11] Blaser (1998) suggested that paying family members for PAS would provide an opportunity for fraud and abuse. In response, Benjamin, Matthias, and Franke (2000) indicated that very little research is available to shed light on the debate, but early studies indicated very little fraud and abuse in these family care giver situations.

Workers with disabilities are reported to be more productive and to require fewer accommodations than employers generally fear (Greenwood & Johnson, 1987; Hernandez, Keys, & Balcazar, 2000). At the most basic level, however, PAS is necessary for more than one half of the people with at least one ADL or IADL limitation; Nosek (1990, p. 2) made the case that "you can't work if you can't get out of bed." Publicly funded agency-based PAS plans generally limit the types of services that may be provided and the number of hours that may be funded. They may also limit consumer input on the caretakers hired (Livermore et al., 2000)[12].

Section 3. Flexible Spending Accounts: History, Access, and Use

Before exploring the relevance of using FSAs for PAS, it is important to understand the history, access, and use of FSAs by employers and employees in the United States. In the late 1970s and early 1980s, the Treasury Department issued new tax regulations regarding employee benefits. In 1978, rules for cafeteria plans provided employers with the option to offer employees a menu of benefits from which to choose (Fox & Schaffer, 1987). These benefits included vacation days, life insurance, and cash benefits, among others. Cafeteria plans were developed as human resources recruitment tools, especially as the labor market transformed with increased participation of women. Because married couples did not need to use employer-provided health insurance plans from both the husband's and the wife's employer, cafeteria plans provided an appealing alternative. Families could be enrolled in the health insurance plan of one of the couple's employers, and the other spouse would be able to select other types of benefits from his or her employer's cafeteria plan (Fox & Schaffer, 1987).

In 1982, the U.S. Department of Treasury issued regulations dealing with employer-provided health care benefits. These regulations were intended to prevent employers from providing expensive tax-free health benefits only to high-level workers. The Treasury wanted to have employers extend tax-free health benefits to all employees. As Fox and Schaffer (1987) showed in detail, these regulations did not anticipate the creation of FSAs. Using the language of the law in creative ways, benefit consultants offered employers FSAs as a new way to provide their employees with additional health benefits at no cost to themselves.

Through FSAs, individuals agree to reduce their take-home pay and put pre-tax money aside for qualified health or dependent care expenses. When the FSA was first established, unused FSA money was returned to the employee at the end of the plan period. Some plans even allowed reimbursements without a selected amount of withholding in the beginning of the year by the employee. Instead, employees were reimbursed with tax-free funds as they submitted health expense claims. The Treasury Department did not like FSAs because when the legislation was proposed the employer, not the employee, was to bear the costs of the benefit (Fox, & Schaffer, 1987). By the time the Treasury issued regulations on the new section of the tax code, FSAs were more or less a fait accompli. Employers favored them, even arguing that they would help reduce health care costs. It was unclear what would happen to the employees who had been using the previously unregulated FSA's for the few years they were in place. Finally, the Treasury ruling allowed FSAs to continue as long as the employee was making

[12] Several states have adopted Cash & Counseling programs that allow consumers to directly hire their caregivers and purchases goods and services related to their personal assistance needs (Nordstrand & Mahoney, 2009). Assessments of these programs report that direct control over the purchase of the services and goods they need has a beneficial impact on both consumers and caregivers. Still, the adoption of such programs varies widely across states and eligibility rules are also a patchwork of state Medicaid rules.

a choice for the health benefit and not choosing indirect compensation. Toward this end, the Treasury determined that the FSAs would include a "use-it-or-lose-it" provision whereby unused money at the end of the plan period is retained by the employer (Fox & Schaffer, 1987).[13]

Kelly (2003) conducted research on the development of dependent care accounts as part of employer-sponsored child care programs. Like Fox and Schaffer's (1987) characterization of health care FSAs, Kelly presented the development of the dependent care FSAs as an outcome of 1981 legislation to create incentives for employer-provided child care benefits in the form of on-site day care centers for which employers would receive tax breaks. Benefit consultants used this legislation as they had the health care regulations: If employees agreed to a salary reduction, the amount reduced would be put into a dependent care pre-tax FSA account. In practice, instead of leading to more employer spending for on-site child care, the legislation was used to promote dependent care FSAs funded entirely by employees themselves. Only later did the Internal Revenue Service (IRS) affirm the legal standing of pre-tax dependent-care accounts.

In 1996, the Small Business Job Protection Act (Sections 137 and 23) introduced employer-provided adoption assistance programs (the adoption FSA) and the adoption credit. Through an adoption FSA, up to $11,650, can be excluded from the employee's taxable wages; although, unlike other FSAs, it is counted as income for the Federal Insurance Contributions Act (FICA) taxes. In addition, if qualified expenses are greater than those available through the FSA, employees also may claim up to an additional $11,650 adoption tax credit (Discovery Benefits, 2008).

The implementation of FSAs spread first among large employers. In 1986, *The New York Times* reported that 90 percent of Fortune 500 companies[14] offered flexible benefits to their employees (up from 12 percent in 1978). FSAs were presented as an important recruiting tool for the companies that offered them. A benefits consultant quoted in the 1986 article noted that the plans were starting to gain popularity at medium-sized firms (Singer, 1986). Recent figures from the U.S. Bureau of Labor Statistics (BLS) (2007) show an imbalance of FSA access among different-sized companies. Large companies are more likely than medium-sized firms to offer FSAs, and medium-sized companies are more likely than small companies to offer FSAs.

The Employee Benefit Survey conducted by the BLS has tracked health and dependent care FSA availability and usage as part of its ongoing reporting of employer-provided benefits. Table 2 shows the percentage of workers with access to FSAs from 2005 through 2008. Survey data on adoption assistance also are included, but the data reflects more than the adoption FSA to encompass other types of employee benefits for adoption.

[13] Barringer and Milkovich (1997) offered an alternative explanation. They suggested the Treasury's concern was with revenue loss and that the use-it-or-lose-it provision would act as a deterrent to participation and reduce contributions to FSAs.

[14] The top 500 U.S. public corporations ranked by their gross revenues.

Table 2. percent of Workers and Companies with Access to Flexible Spending Accounts by Account Type, Selected Characteristics, and Year

Flexible Spending Account Type	Year	percent All Workers	percent Full-Time Workers	percent Part-Time Workers	percent < $15 per Hour	percent > $15 per Hour	percent Companies 1 to 99 Workers	percent Companies 100+ Workers
Dependent Care	2005	29	33	14	18	43	14	47
	2006	30	34	16	19	43	15	47
	2007	31	35	17	20	44	15	48
	2008	34	39	19	N/A	N/A	16	50
Health Care	2005	31	37	15	20	46	16	50
	2006	32	37	16	21	45	16	50
	2007	33	38	17	23	45	17	51
	2008	37	43	19	N/A	N/A	18	54
Adoption[15]	2005	9	11	4	5	15	3	17
	2006	10	12	5	5	16	4	17
	2007	11	12	5	5	17	4	18
	2008	11	13	5	N/A	N/A	4	19

Note. From U.S. Bureau of Labor Statistics (2005, 2006, 2007, 2008)

The proportion of workers with access to health and dependent care FSAs rises slightly each year, and the increase from 2007 to 2008 was more pronounced than in previous years. Access to adoption FSAs is extremely limited. This may be attributable, in part, to the time span between passage of the first two laws in the early 1980s to passage of the later law in 1996. It also may be related to the larger cap which allows access up to 11,000 dollars, over which employers do not have control. Finally, the limited size of the population likely to take up this benefit may reduce the recruiting and retention incentive for the employer associated with health care and dependent care FSAs.

Also, the substantial difference in access to FSAs based on employee characteristics is interesting. For instance, full time workers are more than twice as likely as part-time hires to be offered FSAs. The discrepancies in access are even wider for employees paid hourly wages. Among individuals making more than $15 per hour, 45 percent had access to health care reimbursement accounts, while only 23 percent of employees making less than $15 per hour were offered the benefit in 2007. The widest gap in access, however, is observed in different business sizes. In 2008, only 18 percent of individuals working at companies with fewer than 99 employees had access to health care FSAs, while 54 percent of individuals working for companies with 100 or more employees were offered the benefit.

In light of these discrepancies, some states have been urging small businesses to provide Section 125 cafeteria plans.[16] States' laws governing cafeteria plans vary. Some states mandate that cafeteria plans be offered by all employers who offer health insurance coverage. Other states only encourage

[16] This refers to Title 25, Subtitle A, Chapter 1, Subchapter B, Part III § 125 of the U.S. IRS Code (2002)

small employers to use cafeteria plans as part of expanding health coverage among their employees. State legislators see the tax breaks for both employers and employees that constitute the central feature of cafeteria plans as means to offset the escalating costs of health insurance premiums (Cauchi, 2008). The fact that FSAs provide tax benefits to both employers and employees seems to be central to promoting new state laws. Supporters argue that these tax advantages need to be emphasized to employers and employees to increase FSA availability and enrollment.

FSAs are still only a minor part of employee benefits, and the BLS does not yet collect data on the number of eligible employees who take advantage of them. The studies that we reviewed in this section were based on limited data that may not be representative of the general population. Still, the information available shows that employee participation is quite low. A report by the International Foundation of Employee Benefit Plans (2007) surveyed 326 member establishments in both the public and private sector. Most companies surveyed (61 percent) had an employee participation rate of 29 percent or less in their health-care FSA programs. For the dependent care FSA, the employee participation rate was lower still: 68 percent of employers reported less than 9 percent of their employees took advantage of their dependent care FSAs.[17] Reported forfeiture rates are very low and a substantial share of employers does not keep track of those numbers (International Foundation of Employee Benefit Plans, 2007).

Some researchers have looked into the patterns of usage and spending of money in FSAs. Academics were particularly interested in the factors that explain individual FSA participation and the amounts of money participants choose to allocate to their health care FSAs.[18] These studies usually utilize data from large employers or health insurers of multiple businesses. Schweitzer, Hershey, and Asch (1996) analyzed data from approximately 9,500 University of Pennsylvania employees from 1987 to 1992. In the study, an average of 11 percent of employees contributed in a given year. Variables used in this analysis, such as family status, age, deductible and copayment rates, failed to predict participation levels in any substantial way (Schweitzer, & Asch, 1996; Schweitzer et al., 1996). Because both studies involved just one company each, comparisons between promotional methods were not possible. However, Schweitzer et al. (1996) suggested that human resources professionals can promote the adoption of FSAs by guiding an employee's first benefits decision and by carefully structuring default options.

In a detailed analysis of FSA selections among individuals employed at 15 Minnesota companies, Feldman and Schultz (2001) confirmed previous findings of overall low participation rates in FSAs among eligible employees. They also tested several factors hypothesized to influence contributions to health care FSAs. They looked into health status, use of out-of-network doctors, family education level, and employer strategies for presenting FSAs to employees. They found that single and married participant enrollments differ. Singles are more likely to participate when they are older, while age does not affect family participation. The number of children also does not affect participation. The marginal tax rate[19] was significantly related to participation among families, but not individuals. These findings may indicate

[17] Participation rates for dependent care FSAs would be expected to be lower than for health care FSAs because only individuals with dependents are eligible.

[18] We could find no research on the amounts allocated for dependent care FSAs.

[19] The marginal tax rate is based on the last dollar of income earned. This is very different from the average tax rate, which is the total tax paid as a percentage of total income earned. In 2003, for example, the United States imposed a 35 percent tax on every dollar of taxable income above $155,975 earned by a married taxpayer filing separately. However, that tax bracket applied only to earnings above the $155,975 threshold; income below that cutoff point were still taxed at 10 percent on the first $7,000, 15 percent on the next $14,400, and so on (Reynolds, 2008).

that health care expenses for a typical individual may not be large enough to make the tax savings meaningful, while the health care expenses for a typical family can be expected to be higher, increasing the probability of larger tax savings. PAS expenses, however, do run very high. As a result, the tax burden reduction a PAS FSA creates would be significant even for individuals at lower tax brackets. In other words, as the costs for personal assistance services consume a substantial part of one's income, the incentives for participation is considerably higher for working people with PAS needs.

For high-income families, as noted previously, the tax savings will be greater than for middle- or low-income families. The best predictor of FSA participation was the family's education level (i.e., higher education was linked to higher participation rates), even as the model controlled for income. This may reflect the reduction in the so-called "fear factor" associated with the use-it-or-lose-it requirement; those with higher education may be able to calculate more carefully to ensure that they lose very little or nothing at the end of the plan year. Feldman and Schultz (2001) also looked into the impact of different employer strategies to present FSA options to employees and the relationship of those strategies to participation rates in the plans. The most effective presentation involved special meetings to discuss the benefit. This method was found to increase participation by 7 percent when compared with other methods such as distributing employee benefits brochures. Two FSA program administrators from the State Governor's Office on Employee Benefits (Anonymous, Personal Communication, April 27, 2009; Anonymous, Personal Communication, May 4, 2009) in a large northeastern state mentioned, however, that the cost/benefit ratio of such meetings declines over time. When a new program is introduced, interested employees attend the meeting and decide whether to sign up for it. After a time, however, most interested employees will have learned about the program and face-to-face meetings will attract only new hires, increasing the cost per potential beneficiary. Other strategies commonly used, such as booklets, internal communications, and Web sites did not show meaningful impact on participation rates. This result indicates that employers must play an active role to increase FSA participation.

Cardon and Showalter (2003) examined the use of FSAs by 22,095 policy holders of a medium-sized insurance company. They found that only 2,709 (12 percent) of eligible employees actually participated in the health care FSA. Of these, the vast majority (90 percent) had less than $1 left in their accounts at the end of the year and very few accounts held substantial amounts at the end of the year.

Cardon and Showalter (2003) also analyzed patterns of disbursement of account funds, reporting a spike in use in the beginning of the year with a gradual trailing off for the rest of the year. This result suggests that when participants make the contribution determinations for the next plan year, they consider expected expenses in the beginning of the following year and set aside the necessary funds in the FSA. In practice, health care FSAs are used for highly predictable medical expenses, not as insurance against uncertain expenses. As a result, individuals with predictable medical procedures, such as orthodontic work, are more likely to participate in health care FSAs. Among other variables, Cardon and Showalter found age to be positively related to participation: Older individuals were more likely to participate. Income level and state income-tax rates were statistically significant and had relatively large coefficients, which highlights the larger financial incentives for higher-income individuals and for individuals in states with higher income-tax rates. They found that female-headed households were more likely to participate, which they speculated was a result of women's familiarity with dependent care FSAs. Family size and income also were highly predictive of the amounts participants chose to contribute.

Cardon and Showalter (2003) speculated that as health care FSAs become more widespread, health insurers may start dropping coverage of procedures that are heavily financed by FSA monies. Recent

studies have supported the notion that FSA participation and health insurance plans are associated (Hamilton & Marton, 2008; Jack, Levinson, & Rahardja, 2006). Jack et al. (2006) showed that health insurance plans associated with FSAs have higher coinsurance rates, lower premiums, and members who are likely to face higher marginal tax rates. They contended that the dissemination of FSAs is one of the factors that led to higher out-of-pocket costs for consumers. Hamilton and Marton also found that higher-income individuals are more likely to contribute to FSAs as are older people and women. Even when other factors are controlled, the study showed that minorities have persistent lower levels of participation than Whites.

The findings of the relatively recent and limited literature on FSA participation highlight some problems. In particular, FSA use is skewed toward the most affluent employees, who stand to benefit more from the tax break (Geisel, 2008; Shepherd, 2006; U.S. Congress House Committee on Rules, 2004). This finding may pose serious questions about the fairness of FSAs. In addition, FSA use is still very low among eligible workers. Still, the data also show that access to and participation in FSAs has been growing slowly but steadily, and a strong indication suggests that employee benefit counseling can increase FSA participation.

Expenses currently covered by health care FSAs include the employee's share of the costs for medical, dental, and vision services; deductibles; and the employee's share of the costs for prescription and over-the-counter medications. Dependent care FSAs generally cover work-related day care (including the costs of nursery school, pre-school, kindergarten, summer camp, and before- and after-day program care);[20] the services of a housekeeper, maid, or cook (if the individual also provides care to the dependent); and some medical expenses not claimed elsewhere (U.S. Department of the Treasury, Internal Revenue Service, 2008a) Neither the health care nor the dependent care FSA covers the costs of non-medical PAS. Accordingly, we propose a new stand-alone FSA incorporating the best elements of each of the existing FSAs and adding some new features that will be specific to a PAS FSA.

Section 4. Estimated Numbers of Individuals in Potentially Affected Groups

To estimate the number of individuals who might benefit from a PAS FSA, we used tabulations made by the Center for Personal Assistance Services from public-use micro data of the 2005 American Community Survey and other sources. Three different populations may benefit from an FSA: (1) individuals with disabilities who require non-medical PAS; (2) family and friends who provide unpaid assistance to individuals with disabilities who require non-medical PAS; and (3) non-medical paid PAS providers. In this section, we estimate the numbers of individuals in each of these three groups. The potential impacts of a PAS FSA are explored in Section 6.

Individuals with Disabilities

In 2002, an estimated 8,123,000 individuals reported having at least one ADL or IADL limitation for which they needed PAS (U.S. Census Bureau, 2002). Of these, only 2,617,000 (32 percent) reported working. According to a study by Louis Harris & Associates, Incorporated (1994), nearly one quarter of people with disabilities who were not working full-time cited the need for help from a personal assistant to obtain work and maintain full-time employment status. These findings suggest that the lack of PAS

[20] For children under 13 years and for qualified adults.

may be keeping more than 1,000,000 people with disabilities out of the workforce (Hinton, 2003; Livermore et al., 2000).[21]

The Center for Personal Assistance Services estimates that 3,794,000 working-age individuals with self-care difficulty lived outside of institutions in the United States in 2005. Among them, 646,000 (17 percent) were employed, 124,000 (3 percent) were unemployed but in the labor market, and 3,022,000 (80 percent) were not in the labor force. Figure 1 shows this information graphically.

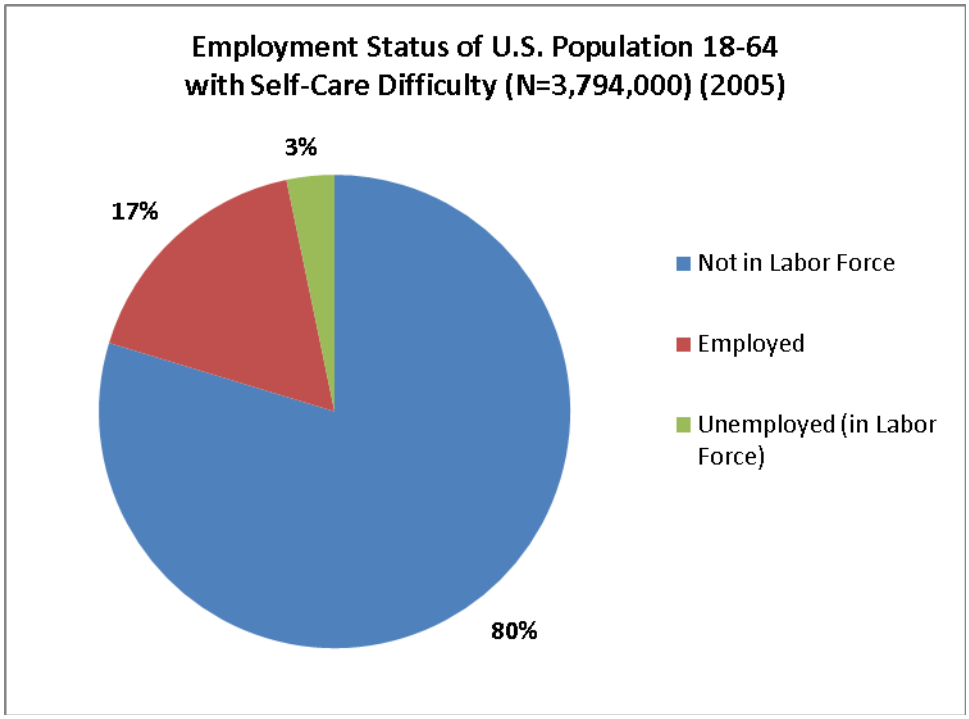

Figure 1. **Employment Status of U.S. Population Aged 18-64 Years with Self-care Difficulty**

These data do not distinguish those unable to work from those who are discouraged from working; that is, some persons with disabilities who would like employment have given up looking for work and so are no longer considered part of the labor force (William Erickson, Employment and Disability Institute, personal communication, March 24, 2009). In 2004, the National Organization for Disability/Harris Poll (Louis Harris & Associates Incorporated (2004) reported that 63 percent of unemployed individuals with disabilities 18 years and older would prefer to be working. However, the data only reflect those individuals who are actively searching for work, and so those desiring employment but not in the labor force likely remain uncounted.

Unpaid Personal Assistance Services Providers

An estimated 44,400,000 Americans provide informal PAS to family members and friends, including assisting with bathing, eating, preparing meals, housekeeping, shopping, managing medications, and

[21] The estimated number of people with disabilities who are not working because of lack of PAS is derived from the 2002 U.S. Census Bureau data and the 1994 Harris study: (8,123,000–2,617,000)/4 = 1,376,500.

other activities of daily living (Feinberg, Newman, Gray, Kolb, & Fox-Grage, 2004). The Family Caregiver Alliance reported that the majority (78 percent) of individuals receiving long-term care at home do so exclusively from a family member or friend. The amount of time caregivers spend providing assistance ranges from less than 1 hour a week to more than 40 hours per week (National Alliance for Caregiving and AARP, 1997)

A typical caregiver in the United States is female (61 percent), approximately 46 years old, has at least some college experience (66 percent), and spends an average of 20 hours or more per week providing unpaid care to someone 50 years or older (79 percent). A majority of caregivers are married, and most have juggled work with caregiving responsibilities at some point during their role as caregiver (National Alliance for Caregiving and AARP, 1997)

Paid Personal Assistance Services Providers

The BLS estimates that personal and home care aides held approximately 595,350 jobs in 2007 at an average hourly wage of $9.11. Nearly one in three direct-care workers serve part-time and according to the BLS, most aides work with a number of different clients with each job lasting a few hours, days, or weeks. “The relatively low skill requirements, low pay, and high emotional demands of the work result in high replacement needs. For these same reasons, many people are reluctant to seek jobs in the occupation” (U.S. Bureau of Labor Statistics, 2007).

Section 5. Potential Impacts of a Personal Assistance Services Flexible Spending Account

A PAS FSA impacts eight potential areas and six stakeholder groups. As shown in Table 3, not all potential impact areas are expected to affect all stakeholder groups.

Table 3. Potential Impacts of a Personal Assistance Services Flexible Spending Account on Stakeholder Groups

	Stakeholder Group					
Impact Area	Public Benefit Recipients with Disabilities Who Require PAS	Individuals in the Labor Force Who Require PAS	Federal Govern-ment	Employers	Unpaid PAS Providers	Paid PAS Providers
Public Benefits	✓		✓		✓	
Taxes and Tax Revenues	✓	✓	✓	✓	✓	✓
Health Insurance and Benefit Security	✓	✓			✓	✓
Recruiting and Workforce Diversity				✓		
Productivity, Health, and Absenteeism		✓		✓	✓	✓
Asset Development	✓	✓			✓	✓
Mental Health, Emotional Health, and Family Relations	✓	✓			✓	✓
Administrative Costs			✓	✓		

Each potential change to the PAS FSA may have one or more (positive or negative) effect on each stakeholder group. A change that is positive for one group may be negative for another. A discussion of the potential impact on each stakeholder group follows with a summary of the findings in Table 4 at the end of the section.

Potential Impacts of a Personal Assistance Services Flexible Spending Account on Public Benefit Recipients with Disabilities

Social Security and Supplemental Security Income (SSI) benefits were provided to a total of 804,787 workers with disabilities in 2007 (U.S. Social Security Administration, 2008). Although the monthly benefit payments range from under $100 to $2,000 or more, the average monthly benefit is $1,054.50. Men receive more than women: on average, $1,187.50 to $900.70 per month.

Some dependents of individuals with disabilities also receive benefits; for example 45,068 wives of individuals with disabilities received an average monthly benefit of $281.00 while 2,515 husbands of individuals with disabilities received an average monthly benefit of $207.80 in 2007. That same year, 902,296 children of individuals with disabilities received an average payment of $279.60 (U.S. Social Security Administration, 2008). If the spouse and child of an individual with disabilities are eligible for benefits, a family of three would have received an average monthly total of $1,615.00 ($1,054.40 + $281.00 + $279.60) and an average annual total of $19,380.00, which is 113 percent of the federal poverty level.[22] An individual with disabilities and requiring PAS who is able to enter or return to the workplace would need to make a salary of at least $40,000.00 to roughly match the public benefits the family of three had been receiving. This figure includes more than $20,000.00 in out-of-pocket costs the employee had not paid while receiving benefits, including

- health insurance (estimated at $3,500 annually) if enrolled in the employer's program;
- health care expenses (estimated at $2,000 annually);
- PAS (estimated at a median level of approximately $7,500 for 17.6 hours per week);
- FICA tax (estimated at $2,480);
- Federal Unemployment Tax Act (FUTA) tax (estimated at $434); and
- income tax (estimated at approximately $5,201 using 2008 tax tables, married filing jointly) minus a $1,000 child tax credit and $235 earned income credit.

If this individual were able to contribute $7,500 to a PAS FSA, the taxable salary would be reduced to $32,500, saving the employee $65 in FICA and $1,125 in income taxes, which the employee could spend elsewhere or save. While this may be helpful in the short-term, Cardon and Showalter (2003) called this strategy "borrowing from the future" because Social Security benefits, which are calculated from reported income, will be reduced at retirement. While higher-income individuals enjoy more protection from this risk (Baxendale, 1993), lower- and middle-income workers should carefully weigh the possible impact of FSA use on Social Security earnings.

Individuals with disabilities are disproportionately poor. According to the 2006 American Community Survey, 25.4 percent of working-age people with any disability versus 9.2 percent of

[22] In 2007, the federal poverty level for a family of three in the contiguous 48 states was $17,170; in Alaska, it was $21,470 and in Hawaii it was $19,750.

working-age people with no disability had incomes below the poverty level (U.S. Census Bureau, 2006). The Medicaid average annual enrollment for fiscal year 2008 was estimated to include 8,500,000 individuals with disabilities (CMS, 2008), and asset poverty[23] estimates run as high as 80 percent among people with disabilities (Morris, 2004). Currently, workers who pay for PAS may recoup some of their expenses as impairment-related work expenses (IRWE) under Section 67(d) of the Internal Revenue Code, but the refund will come from post-tax dollars (Litvak, 1992). With a PAS FSA, an individual who had previously paid out-of-pocket and was refunded via an IRWE would be able to purchase from 20 to 40 percent more service or, alternatively, build assets.

Potential Impacts of a Personal Assistance Services Flexible Spending Account on Individuals in the Labor Force

As was the case with individuals requiring PAS who are entering or reentering the labor market, already-employed individuals using FSAs would save money on their out-of-pocket PAS expenses as well as on FICA and income taxes. Money would be withheld from their regular paychecks and they too would need to weigh the current benefit with the potentially reduced Social Security income available to them at retirement. The savings produced by the new flexible spending account, however, could potentially allow individuals to build assets and weather periods of financial stress more soundly, without sliding into disability rolls.

Potential Impacts of a Personal Assistance Services Flexible Spending Account on the Federal Government

When an individual enters the workforce and no longer receives Social Security or SSI funds, the government is spared the costs of the benefits that would have been paid. For the hypothetical individual previously described (married with one child), the savings would come to $19,380 plus any associated reduction in administrative costs. In addition, providing a mechanism for workers with disabilities to access PAS also may reduce usage of government benefits they may still receive. A study of the Massachusetts Medicaid Program in which PAS was funded for working people with disabilities found that workers utilizing PAS used 74 percent less in non-PAS Medicaid expenses compared to the non-working Medicaid recipients utilizing PAS; in the study, the researchers controlled for the presence of other insurance, disability severity, and demographic characteristics (Hashemi, Glazier, Hooven, & Himmelstein, 2003).

In addition to the savings in benefit payments, the federal government would receive additional tax revenue from individuals with disabilities entering and reentering the labor force and from their employers. As outlined above, an entering or returning employee with disabilities with a spouse and child would pay FICA taxes (estimated at $2,480), FUTA taxes (estimated at $434), and income taxes (estimated at approximately $5,201 using 2008 IRS tax tables). The employer would pay the same amount in FICA taxes (i.e., $2,480) but the law rewards timely payments by reducing the employer's FUTA from 6.2 to .08 percent. Thus, the employer would pay $36 in FUTA tax for that employee. For individuals with disabilities already employed, however, a PAS FSA would reduce government revenues through the loss of both the employee's and the employer's FICA and income tax on moneys set aside.

[23] Asset poverty is a measure of whether a household can support itself using savings or other available assets for 12 weeks at a poverty-level income.

To the extent that a PAS FSA encourages employees to pay formerly unpaid caregivers or document the pay of caregivers who were formerly paid under the table, federal tax revenues will increase as these individuals file and pay their taxes.

Potential Impacts of a Personal Assistance Services Flexible Spending Account on Employers

Employers who offered a PAS FSA would reduce their payroll by the amounts set aside in the pre-tax accounts, and as outlined above, reduce the amount of FICA and FUTA taxes they would have to pay for the employee with a PAS FSA. In addition, the easier budgeting and saving for the employee with a PAS FSA may translate to greater productivity among employees with disabilities needing PAS and among informal caregiver employees.

For the employers, the only negative to adding another FSA to an existing cafeteria plan may be an increase in the administrative costs to run the plan. However, estimates indicate that these costs are very low: approximately $100 dollars per account per year (Employee Benefit Research Institute, 2004).

Potential Impacts of a Personal Assistance Services Flexible Spending Account on Unpaid Providers

Generally, the individuals for whom unpaid workers provide care require help with from one to four ADLs and three to five IADLs (National Alliance for Caregiving and AARP, 1997). Caregivers who provide more or difficult care are much more likely than those with lighter or easier loads to report negative economic effects from the work (Lynn, 2004; National Alliance for Caregiving and AARP, 1997) In one study, family caregivers lost about $650,000 on average over a lifetime; this figure includes lost wages, Social Security, and pension benefits (Metropolitan Life Insurance Company, 1997) In addition, unpaid caregivers sometimes face fatigue, back problems, or other physical or mental health issues that can result in increased absenteeism and reduced productivity in the workplace (Foster, Brown, Philips, & Carlson, 2005). If formerly unpaid PAS providers receive compensation for part of the time they provide care, both their incomes and their potential retirement benefits can be expected to increase as may their ability to build assets. Being able to pay for all the services of a formerly unpaid caregiver may translate to a reduction in the hours needed at a second paying job or increased productivity while on the job. Alternatively, hiring a paid caregiver instead of a friend or family caregiver will allow the latter to accept or return to a full-time job, increasing the former caregiver's income, augmenting asset development, and building potential retirement benefits.

Some researchers posit that paying family members to provide PAS, which is "generally seen as fulfilling a moral duty," could weaken family bonds and complicate family dynamics by introducing an employer-employee relationship to the family unit (Benjamin, 2001). Contrary to that theory, Foster et al. (2005).found that participation in the Medicaid Cash and Counseling Demonstration[24] did not seem

[24]The Cash & Counseling Demonstration program is sponsored by the Robert Wood Johnson Foundation, the Office of the Assistant Secretary for Planning and Evaluation in the U.S. Department of Health and Human Services, and the Administration on Aging. Beginning in 1998, the program "offered Medicaid consumers who have disabilities more choices about how to get help at home. Specifically, it gives … adults with disabilities the option to manage a flexible budget and decide for themselves what mix of goods and services will best meet their personal care needs…. Participants may use their budgets to hire their own personal care aides as well as purchase items or services, including home modifications that help them live independently. The Cash & Counseling Vision

to affect caregivers' perceptions of their relationships with care recipients and, in fact, it "may have improved the quality of their care-related interactions."

According to Foster et al. (2005), one third of unpaid providers describe caregiving as "emotionally stressful." In addition, 15 percent of unpaid caregivers suffer physical or mental health problems as a result of their caregiving, and they experience higher rates of depression, self-reported stress symptoms, and higher use of psychotropic drugs. One half of unpaid caregivers say that providing care detracts from time spent with other family members (Foster et al., 2005).

Potential Impacts of a Personal Assistance Services Flexible Spending Account on Paid Providers

According to a 2009 BLS report, hourly pay for personal and home care aides ranged from $6.84 to $12.33 in 2008. To estimate an annual wage, the BLS multiplied the hourly mean wage by 2,080, the standard number of hours worked for a full-time employee. Using that formula, it determined the estimated average wage for these workers ranged from $14,230.00 to $25,650.00 (U.S. Bureau of Labor, 2009). However, as noted previously, PAS providers generally work part-time, often with more than one client, and are not usually paid for travel between clients. Thus, the annual earnings estimates based on a 2,080-hour work year are likely to be significantly higher than the amounts such workers actually earn. Their earnings are low, in part, because many people hire personal assistants through bonded and insured home-care agencies to avoid taking on the role of employer and related liabilities. In those cases, the client pays significantly more to the agency than the care provider receives. In many cases, personal assistants lack the education and skills that would enable them to get a job outside of the service sector. Although some jobs may pay more, most of their employment opportunities pay minimum wage.

Individuals with disabilities may feel in a position to access more needed care or pay more to caregivers if the PAS funds are accruing tax free. Even if a caregiver works for an agency, such a change might enable the caregiver to limit the number of clients and reduce the time spent traveling from job to job and thus earn better wages. Those hired directly would not need to split the fee with an agency and thus increase their earnings. Even a modest increase in their take home pay or a reduction in the unpaid time they spend traveling between clients will result in increased income, more potential Social Security benefits, and possible asset development.

Like their unpaid counterparts, paid PAS providers report emotional stress and physical and mental problems associated with caregiving (Larson & Lubkin, 2009). To the extent that a PAS FSA facilitates ongoing relationships between individuals with disabilities and particular PAS providers, the caregivers may be able to reduce stress, improve mental and physical health, and exert more control over their schedules.

Table 4 summarizes the positive and negative potential impacts of PAS FSAs for each stakeholder group.

Statement fully describes the essential components of the model" (Cash & Counseling, 2007). (Although grant funding ended in 2009, the 15 Cash & Counseling states continue to operate their projects.)

Table 4. Positive and Negative Potential Impacts of Personal Assistance Services Flexible Spending Accounts

Stakeholder Group	Potential Impacts
Public benefits recipients with disabilities who require PAS	**Positive:** • Entry or reentry into the labor market • Enhanced independence • Pre-tax dollars to pay for PAS
	Negative: • Pay for services they were previously getting without expense • Pay income taxes • Money withheld from paychecks • Potential reduction in Social Security income at retirement
Individuals in the Labor Force who Require PAS	**Positive:** • Pre-tax dollars to pay for PAS
	Negative: • Money withheld from paychecks • Potential reduction in Social Security income at retirement
Federal government	**Positive:** • Reduced benefit expenditures • Increased tax revenue on wages
	Negative: • Reduced tax revenue from money set aside in pre-tax account
Employers	**Positive:** • Reduced payroll taxes (for PAS FSA participants) • Enhanced workforce diversity • Productivity of employees with disabilities • Productivity of formerly unpaid caregivers
	Negative: • Administrative costs
Unpaid PAS Providers	**Positive:** • Pay for formerly unpaid labor • Improved mental health • Improved physical health • More control over schedule • Contribute to Social Security • (Depending on wage) eligible for unemployment insurance

Paid PAS Providers	**Positive:** • More control over schedule • Improved mental health • Improved physical health • Potential for more take-home pay • Potential for more retirement benefits • Potential for more asset development
	Negative: • (If earn more) pay higher income taxes

Section 6. The Extent to Which Incentives to Work May be Offset by Work Disincentives

As noted earlier, when individuals with disabilities lose public health-care benefits as a result of employment, the advantages and disadvantages of entering the workforce must be weighed carefully. In this section, we provide a descriptive analysis that simulates the effect of additional post-tax income that could be potentially available to people with disabilities that choose to use PAS FSAs after reentering the workforce. We used data from the 2006 Medical Expenditure Panel Survey Household Survey Dataset (MEPS) (Agency for Healthcare Research and Quality, 2006) to simulate the effect of a PAS FSA. MEPS is a large-scale survey of families and individuals that collects information on respondents' health status, employment status, and the cost and utilization of health care and health insurance. The MEPS data set used for this analysis was the 2006 Full Year Population Characteristics file, which is comprised of three quarterly surveys of the same respondents. We used these data to study post-tax incomes of respondents and used odds-ratios to calculate the likelihood of a MEPS respondent returning to work at 6-month and 12-month follow-ups**.**

To simulate the effect of additional post-tax income on the likelihood of employment, we used odds-ratios to determine whether the probability of people unemployed due to illness or disability will return to work is the same at progressively higher income levels. Odds-ratios provide the likelihood of an event (in this case, a return to work) occurring in one group (in this case, defined as a baseline income level) compared with the likelihood of the same event occurring in another group (in this case, a higher income level). Table 5 indicates that respondents who were unemployed at baseline due to factors other than disability have a much higher likelihood of being employed at 6-month and 12-month follow-up points than were those whose disability was primarily responsible for the unemployment. For example, of the unemployed (at baseline) MEPS respondents without disability or illness reasons for unemployment, 80.95 and 92.13 percent were working at the 6- and 12-month follow-up, respectively; however, 2.97 and 4.00 percent of those unemployed at baseline due to illness or disability were working at the 6- and 12-month follow-up.

Table 5. Employment Status at 6- and 12-Month Follow-Ups by Reason for Unemployment at Baseline

	Unemployed at Baseline	Employed at 6-Month Follow-Up	Unemployed at Baseline, Employed at 12-Month Follow-Up
Unemployed for Non-Disability Reasons	A_1 18,102	A_2 14,654 **80.95 percent**	C_1 16,678 **92.13 percent**
Unemployed Due to Illness or Disability	B_1 1,349	B_2 40 **2.97 percent**	C_2 54 **4.00 percent**
Total	19,451	14,694	16,732

Note. Agency for Healthcare Research and Quality (2006)

The odds-ratio for the difference in likelihood of the two groups returning to work at the 6-month follow-up was calculated by multiplying the column percentages in Cell A_1 by Cell B_2 and Cell A_2 by Cell B_1 and dividing the products (Cell A_1*Cell B_2/Cell A_2*Cell B_1) for the 6-month follow-up. The probability of returning to work was greater (.931*.694/.997*.027=23.93 percent) for respondents who were unemployed due to non-disability reasons, than for those reporting an illness or disability as the reason for their unemployment. This odds-ratio decreased slightly (to 23.07 percent) at the 12-month follow-up.

To simulate the use of a PAS FSA, we varied the income levels of different groups. For example, we compared income groups to determine if respondents with higher incomes were more likely to return to work than those with lower incomes. The analysis includes one covariate (type of insurance) and only respondents who reported being unemployed due to disability or illness at baseline (see Table 6).

In Table 6, the *all income levels* category serves as a baseline odds ratio.[25] As shown in the table, at the 12-month follow-up, respondents who were unemployed at baseline due to illness or disability and had private insurance coverage were 10.7 percent more likely to return to work than those enrolled in a subsidized, public, health care program. Those enrolled in a public, subsidized, health care program were 4.0 percent less likely than their uninsured counterparts to return to work at the 12-month follow-up.

Through the analysis, we found a positive correlation between income and return to work: An increase in income appears to be associated with an increase in the likelihood of returning to work among people for whom illness or disability had kept them out of the labor market. When we controlled for respondents whose income was 20 percent above the average household income of a MEPS respondent, the 10.7 percent income advantage for those with private health insurance versus subsidized, public, health care increased to 11.2 percent. This change equals a 4.5 percent increase in the employment rate for respondents who were unemployed due to illness or disability and had private insurance. The 4.0 percent income advantage for those with public health care versus those who were

[25]The cross-tabulation table is not included in the text.

uninsured at baseline increased to 5.7 percent when controlling for incomes 20 percent above the average. This change equals a 14.9 percent increase in the employment rate. These findings indicate that an increase in post-tax income from the availability of a PAS FSA could lead to a slight increase in the percentage of people returning to work after being out of the workforce due to disability or illness.

Table 6. Income-Related Odds-Ratios of Employment at 12-Month Follow-up among Medical Expenditure Panel Survey Respondents Who Reported Having Been Unemployed Due to Illness or Disability at Baseline, 2005-2006

Insurance Status of Unemployed at Baseline due to Disability or Illness	Odds-Ratio of Employment			
	All Income Levels	Income + 10 percent	Income + 15 percent	Income + 20 percent
Private vs. Public Health Care	10.7 percent	11.2 percent	10.4 percent	11.2 percent
Uninsured vs. Public Health Care	4.0 percent	3.7 percent	4.7 percent	5.7 percent

Note. Agency for Healthcare Research and Quality (2006)

Section 7. Alternative Tax-Benefitted Funding Mechanisms for Personal Assistance Services

Several existing end-of-year tax deductions and potentially adaptable pre-tax benefits also might fund in-home PAS for employees. Health savings accounts (HSAs), dependent care FSAs, and the IRWE income tax deduction came up frequently in our conversations with human resources practitioners, benefits administrators, and individuals with disabilities.

Health Savings Accounts

Some cafeteria plans include HSAs, in which pre-tax money to pay for the qualified medical expenses of the employee, the employee's spouse, or the employee's dependents (U.S. Department of the Treasury, Internal Revenue Service, 2008b). In the same way health FSAs cover health care expenses not covered by an individual's health insurance plan, HSAs may be used to cover deductibles, co-payments, and prescription and non-prescription medicines. Unlike FSAs, HSAs are portable, moving with the employee from one job to the next. Self-employed individuals also are eligible for HSAs.

An HSA beneficiary must have a high-deductible health plan (HDHP), insurance plans that have a minimum annual deductible level of at least $1,100 for individuals and $2,200 for families and a maximum annual out-of-pocket payment level of $5,600 for individuals and $11,200 for families. Beyond the maximum, insurers must pick up 100 percent of the medical expenses. HSAs were first made available in 2003. They were designed as a way to increase incentives for cost control among health care users and thereby limit or stop premium increases. The strategy for combining HSAs and HDHPs is based on the rationale that individuals will be more mindful managers of their health care costs if they have high deductibles and are therefore paying more of the cost of medical expenses themselves.

With such high deductibles, insurers are less exposed to more mundane health care expenses, while beneficiaries are still insured against high, unexpected costs and fully covered for catastrophic events

that surpass the maximum annual out-of-pocket expenses. As a result, the premium costs for a HDHP are lower than those of a standard employer provided health care plan. That premium differential allows for employers to contribute to the employees' HSA funds. In addition to cost reduction, supporters of HSAs believe they return much of medical treatment decisions to patients, a cornerstone of the "consumer-driven" health insurance model (Scandlen, 2007). Opponents of HSAs argue that they may lead to pool selection problems as healthier individuals will flock to the less costly premiums and leave more comprehensive and generous health plans for less healthy people. They also argue that high deductibles may lead to delay in diagnosis and treatment for individuals with limited funds to spend to meet the high deductible level (Collins, 2006).

Employers like HSAs because the HDHPs have significantly lower premiums than other insurance plans. Employers generally save so much in premiums, in fact, that they may join the employee in contributing to the HSA.

Currently, HSA funds cannot be used to fund PAS plans that are not medically related. For many individuals with disabilities, an ongoing need for assistance with ADLs or IADLs requiring PAS is not necessarily medical in nature. Neither private health insurance plans nor HSAs cover the costs of non-medical PAS.[26] To meet the needs of the individuals with disabilities with non-medical PAS needs, HSAs would need to cover non-medical PAS. While the funds for HSAs could be adapted to reimburse PAS, they would likely not be counted as part of the high annual deductible because private insurers do not cover non-medical PAS.[27] Adding non-medical PAS funding to HSAs might lead to negative consequences if limited dollars force individuals to choose between covering necessary health care or PAS expenses.

In addition, because of the stigma of the medical model discussed at the beginning of this paper, the name of the account allowing for PAS would need to be changed. As all of the other expenses associated with HSAs are health related, the best name option would likely still include the word *health*: for example, *Personal and Health Care Account*, and therefore, be unacceptable to some individuals with disabilities.

Impairment-Related Work Expenses

The IRWE income tax deduction enables individuals with disabilities to deduct IRWEs on their federal income tax returns. IRWE deductions do not have a lower or upper limit as other deductions sometimes do: All qualifying expenses necessarily incurred for the individual to be able to work may be claimed as a deduction, and PAS expenses qualify for the IRWE deduction.

To benefit from the IRWE deduction, individuals must itemize their tax returns and document the funds spent. To itemize deductions, individuals must forgo the standard deduction option offered to all taxpayers ($5,450 in 2008 for a single individual). Any individual filing federal income taxes may choose the standard deduction amount, which reduces the income base on which one's income tax is assessed. For itemizing to be financially worthwhile, the sum of the qualified itemized deductions must surpass the amount of the standard deduction. For a single individual without any other types of qualifying expenses for deductions (such as real estate taxes, state income taxes, state sales taxes, or medical

[26] Public plan coverage of PAS is limited and varies substantially across states (LeBlanc, Tonner, & Harrington, 2001).

[27] A similar problem would arise if the IRS allowed non-medical PAS to be reimbursed through health care FSAs. Because employers usually limit the overall amount of contributions to health care FSAs, individuals with no PAS needs would be able to use their tax-free dollars for medical expenses, but those with PAS needs would face a trade-off between their medical and PAS expenses.

expenses above 7.5 percent of adjusted gross income), a $5,000 PAS bill used as a IRWE deduction would not translate into tax relief because the standard deduction would represent a larger reduction in the income on which the tax burden is assessed by a difference $450. In this scenario, the individual would select the standard deduction.

If the same individual had paid $10,000 for PAS that year, the deduction would result in tax relief ($10,000-$5,450=$4,550) when compared to the standard deduction. However, a $10,000 PAS bill would give the claiming taxpayer an income reduction of only $4,550. In practice, this means that only a fraction (the share that surpasses the level of the standard deduction) of the individual PAS expenses may be translated into tax relief.[28] Because certain groups have even higher levels of standard deduction (i.e., married individuals filing jointly, the blind, and those over the age of 65) the magnitude of the IRWE expenses must be large for it to represent actual tax relief. In contrast, according to the amount selected by the beneficiary, a FSA withholds funds from each paycheck before taxes are assessed on income. As a result, a $10,000 FSA devoted to PAS translates into a $10,000 income reduction and the taxpayer is still entitled to the standard or itemized deduction.

When compared to the tax savings presented by a FSA, the IRWE deduction presents additional disadvantages. The individual claiming an IRWE deduction must wait for tax return season to recoup some out-of-pocket expenses. In addition, evidence from the earned income tax credit research indicates that tax benefits that need to be claimed in one's tax returns pose a barrier to a share of potential beneficiaries. That is, a significant percentage of eligible individuals do not file taxes or claim the credit to which they are entitled, leaving money "on the table" (Holt, 2006).[29]

Dependent Care Flexible Spending Accounts

Dependent care FSAs reimburse individuals for non-medical PAS on the condition that the care is provided to a dependent. However, working individuals with PAS needs may not use a dependent care FSA to pay for their own personal assistance. To overcome this issue, the FSA might be changed to allow working individuals to set aside pre-tax dollars for their own PAS.

The current cap is the most significant limitation of the FSA PAS proposal. By law, no matter how many dependents an individual may have, contributions are limited to $5,000 annually. An employee with 1 or 10 dependents could only set aside a maximum of $5,000. Adding the individual employee to the mix would only reduce the per-person pre-tax benefits. If the legislation changed the cap to allow $5,000 for each individual (employee or dependents) the problem would be eliminated. The benefit name would need to be changed from "Dependent Care FSA" to include the individual (e.g., "Self and Dependent Care FSA"). This solution would be problematic as the new benefit would affect a very large number of individuals, having a much larger impact on government revenues.

Adding PAS for the working individual to the dependent care FSA would yield some obvious benefits. First, it would require less controversial legislation as the change only adds eligibility to an existing cafeteria plan option. Instead of creating a new FSA with a particular group in mind, this solution would

[28] An individual with several qualifying itemized deductions could take advantage of an IRWE deduction for the full amount of expenses if the amount of the other deducted items surpasses the level afforded in the standard deduction.

[29] A number of potentially eligible individuals simply fail to file taxes or claim the credit. The research notes that over the 3 decades of existence, the earned income tax credit has been increasingly utilized and the current rate is quite high.

extend the current benefit to the working individuals, allowing for reimbursement of at least some PAS costs.

Perhaps the greatest advantage of adding eligibility to the existing dependent care FSA involves the relatively quick adoption rate of such a program compared to that a brand new FSA. As shown in Table 2, the most recent data indicate that less than one half of all workers are offered a FSA, even though the plans were first introduced more than 2 decades ago. In addition, the adoption rate of FSAs varies by business size and characteristics of the workforce. The passage of legislation creating a new PAS FSA would likely be adopted relatively slowly because of the limited demand.

Alternatively, changing the dependent care FSA to include PAS for the employee means that, in practice, implementation would be almost immediate, and employees who currently use the dependent care FSA benefit would be able to take advantage of pre-tax dollars to cover the costs of their own PAS. Individuals with PAS needs would have access to a large number of businesses that already offer dependent care FSAs. Finally, because the population eligible to participate in a dependent care account is larger than the population needing PAS, businesses will likely be pressured to align with the benefit practices of competitors and offer the dependent care FSA, while such incentives would not exist for establishing a new PAS FSA.

Table 7: Estimating the financial impact of FSAs on individual income

John Doe is a 36-yr-old male with disabilities who is married with 1 child. He currently earns $ 43,000.00 a year. In order to work he uses Personal Assistance Services and Dependent care services. To illustrate the impact of a FSA for PAS on his income, this table compares how the use of FSAs impacts his take-home income, purchasing power and savings potential. The three scenarios presented below show the financial outcomes of (1) he does not utilize any FSA for his expenses (as in the case of using the federal income tax itemized deduction as IRWE's), (2) he only utilizes the dependent care FSA, as it exists today for his qualifying child care expenses, and finally the outcome of his access to and subsequent use of a FSA for PAS in addition to the dependent care FSA.*

	Scenario 1: John Utilizes IRWE deductions in order to obtain tax relief for his PAS.	Scenario 2: John uses the Dependent Care account, as it exists today ($5,000 Maximum),	Scenario 3: John has an available FSA for PAS services ($10,000) in addition to the Dependent Care FSA ($5,000)
Gross Income	43,000.00	43,000.00	43,000.00
FSA Contributions Per Pay Period	0.00	192.30	576.00
Net Pay Per Pay Period	1,386.85	1,238.00	940.59
Adjusted Pay Per Pay Period (Net +FSA Contributions)	1,386.85	1,430.30	1,516.59
Dependent care and PAS Expenses Per Pay Period	Dependent: 192.30 PAS: 384.00 Total : 576.00	Dependent: 192.30 PAS: 384.00 Total : 576.00	Dependent: 192.30 PAS: 384.00 Total : 576.00
Discretionary Income After Expenses Per Pay Period	810.85	854.00	940.59
Taxable Income after FSA/ IRWE Deductions**	43,000.00	38,000.00	28,000.00
Annual Federal Income Tax Burden	2,434.00	1,684.00	663.00
Paycheck Savings	0.00	43.00 Bi Weekly 86.00 Monthly 1,032.00 Annually	129.35 Bi Weekly 258.70 Monthly 3,104.40 Annually

**Note: This scenario is a conservative estimate of costs, there is no state taxes factored in, as these vary across states and itemized deductions outside of IRWE's are not considered in order to preserve the integrity of the scenario's data.*

***Note: Based on a married, filing jointly tax form.*

Table 7 compares the impact of the use of flexible spending accounts on the income levels and purchasing power of participants with those of individuals who choose not to use the accounts, but do have the same levels of targeted expenses. In the scenarios presented above, a married individual with one child earns $43,000 annually. He has fixed qualifying expenses with child care and personal assistance services, $5,000 and $10,000 respectively. In the first scenario, the individual pays for these expenses out-of-pocket, using the post-tax earnings from his job. In the second scenario, he uses the dependent care FSA to set aside $5,000 annually for his qualifying child care expenses. In the third scenario, he takes advantage of both the dependent care FSA and the PAS FSA to pay for his qualifying

expenses in child care and personal assistance services. As the table shows, under the first scenario the net paycheck compensation is higher, as the individual does not set aside moneys for his targeted expenses. However, as line 4 indicates, if the individual sets aside moneys in the FSA his overall purchasing power is higher. While in the first scenario, the worker takes home $1,386 in bi-weekly net pay, he has to use $576 out of his paycheck to pay for child care and personal assistance services. Once these expenses are accounted for, his discretionary bi-weekly income falls to $810.85. If the same individual could take advantage of a child care FSA for the $5,000 in annual expenses he needs, he would still have to use part of his net pay to purchase personal assistance services, but his take home discretionary pay would be slightly higher at $854. This difference is due to the fact that his annual gross income is now $38,000, as he set aside $5,000 for dependent care. His bi-weekly paycheck deduction for this FSA comes to $192.30, but his federal withholdings and other payroll taxes are now based on the lower gross income figure. His annual paycheck savings from using a $5,000 dependent care FSA amount to $1,032.00.

Additionally, his federal income tax burden would also be reduced. While individual in the first scenario would have a federal income tax burden of $2,434, with the $5,000 dependent care FSA, his federal income tax burden would be reduced to $1,684. This estimation takes into account the fact that in the first scenario, the individual would be able to use the Impairment Related Work Expenses (IRWE) deduction. However, he would need to itemize his deductions. In 2008, a married individual filing jointly could claim the standard deduction of $10,900 in his income tax form. His qualifying IRWE would allow him to claim $10,000 in itemized deduction, but he would have to forgo the standard deduction. In the case of an individual who does not have qualifying expenses for his itemized deductions form, the standard deduction would be more valuable. As a result, it would not be worth claiming the IRWE deduction and his PAS expenses would not alleviate his income tax burden.

The use of a PAS FSA account in addition to the dependent care FSA yields the most savings for the individual described. Under scenario 3, he is allowed to set aside $5,000 for dependent care expenses and $10,000 for personal assistance services annually. In this situation, the individual would have discretionary income (after paying for dependent care and personal assistance services) of $940.59 bi-weekly. His federal income tax burden would fall to $663, as his gross income would not include the $15,000 set aside for FSAs. In addition, in paycheck deductions alone, the individual would save $3,104.40 annually. This represents the amount of discretionary income he would have when compared to an individual with the same dependent care and personal assistance services expenses who does not utilize FSAs. Over the course of ten years, using very conservative investments that yield a 6.5 percent annual interest rate, these savings would amount to over $43,500, while keeping the individual employed. These investments would allow the individual to boost his independence as he would be better able to weather periods of financial difficulty, fund educational advancement, own a home or his own business etc.

Section 8. Draft Legislation for a Personal Assistance Services Flexible Spending Account

New legislation will be required to implement a PAS FSA, specifying eligibility, qualified services, qualified providers, and required reporting mechanisms. Proposed legislation, adapted from existing law is presented below.

Personal Assistance Services Flexible Spending Account Legislation

(1) **Eligible employee**[30]

(A) **In general**

The term "eligible employee" means any employed individual who has been certified by a licensed health-care practitioner as—

(i) being unable to perform (without substantial assistance from another individual) at least 1 activity of daily living for a period of at least 90 days due to a loss of functional capacity,

(ii) having a level of disability similar (as determined under regulations prescribed by the Secretary in consultation with the Secretary of Health and Human Services) to the level of disability described in clause (i), or

(iii) requiring substantial supervision to protect such individual from threats to health and safety due to severe cognitive impairment.

Such term shall not include any individual otherwise meeting the requirements of the preceding sentence unless within the preceding 12-month period a licensed health-care practitioner has certified that such individual meets such requirements.

(B) **Activities of Daily Living**

For purposes of subparagraph (A), each of the following is an activity of daily living:

(i) Eating.

(ii) Toileting.

(iii) Transferring.

(iv) Bathing.

(v) Dressing.

(vi) Continence.

(C) **Employed Individual**

(i) For purposes of subparagraph (A), each of the following is an employee: Common-Law Employee,[31] providing that the individual is not a dependent of the individual who requires Personal Assistance Services. (ii) Self-employed individual.[32]

(a) **In general**

The term "employee" includes, for any taxable year, an individual who is a self-employed individual for such taxable year.

(b) **Self-employed individual**

The term "self-employed individual" means, with respect to any taxable year, an individual who has earned income (as defined in paragraph [2]) for such taxable year. To

[30] With one change, the definition above is identical to that of a "chronically ill individual" from Title 26 > Subtitle F > Chapter 79 > §6602B of the Health Insurance Portability and Accountability Act, Treatment of qualified long-term care insurance). The change reduces the number of required activities of daily living with which the individual requires assistance from 2 to 1.

[31] Under common-law rules, anyone who performs services is an employee ***if the person needing service can control what will be done and how it will be done.*** This statement applies even when the employer gives the employee freedom of action. The salient point is that the person needing the service has the right to control the details of how the services are performed (Internal Revenue Service, [IRS], 2008) (http://www.irs.gov/businesses/small/article/0,,id=179112,00.html)

[32] The definition is identical to that of Title 26 > Subtitle A > Chapter 1 > Subchapter D > Part I > Subpart A > § 401 in the I.R.S. code (Qualified pension, profit-sharing, and stock bonus plans) > (c) Definitions and rules relating to self-employed individuals and owner-employees > (1) (Self-employed individual treated as employee).

the extent provided in regulations prescribed by the Secretary, such term also includes, for any taxable year—

(1) an individual who would be a self-employed individual within the meaning of the preceding sentence but for the fact that the trade or business carried on by such individual did not have net profits for the taxable year, and

(2) an individual who has been a self-employed individual within the meaning of the preceding sentence for any prior taxable year.

(2) **Qualified FSA services**[33]

For purposes of this section—

(A) **In general**

The term "qualified personal assistance services" means maintenance or personal care services, which—

(i) are required by an eligible individual as described in subparagraph (A), and

(ii) are provided pursuant to a plan of care prescribed by a licensed health-care practitioner.

(iii) qualified services include:

(a) Personal care.
(b) Bathing.
(c) Toileting.
(d) Grooming.
(e) Transferring.
(f) Simple wound care.
(g) Meal preparation/feeding/cleanup.
(h) Light housekeeping.
(i) Laundry.
(j) Medication reminders.
(k) Dressing.

(3) **Qualified FSA providers**[34]

An amount paid for qualified personal assistance services (as defined in section [C]) provided to an individual may be paid for with PAS FSA funds provided that the provider is not a dependent of the individual receiving the service.[35] This includes—

(A) the spouse of the individual receiving services,

(B) the dependent child of the individual receiving services,

(C) the dependent adult claimed on the tax return of the individual receiving services, or

(D) by a corporation or partnership that is related (within the meaning of section 267[b] or 707[b]) to the individual.

(4) **Reporting requirements**[36]

[33] Derived from Title 26 > Subtitle F > Chapter 79 > §6602B in the I.R.S. code(Treatment of qualified long-term care insurance).

[34] Derived from the Health Insurance Portability and Accountability Act of 1996 > Title III Tax-related Health Provisions > Subtitle C Long-term Care Services and Contracts > Part 1 General Provisions > § 322 > (11) (Certain payments to relatives treated as not paid for medical care).

[35] Federal Medicaid regulations prohibit federal payment to "legally responsible" family members (e.g., spouses or parents of minors), and states "vary in the extent to which other family members may be reimbursed with public funds. Some States have a long list of excluded relations, including grandparents, grandchildren, and in-laws" (Benjamin, 2001). These regulations will need to be reviewed carefully and revised appropriately.

(A) **In general**
Any person who pays for personal assistance services shall make a return, according to the forms or regulations prescribed by the Secretary, setting forth--
(i) the aggregate amount of such benefits paid by such person to any individual during any calendar year,
(ii) whether or not such benefits are paid in whole or in part on a per diem or other periodic basis without regard to the expenses incurred during the period to which the payments relate,
(iii) the name, address, and TIN of such individual, and
(iv) the name, address, and TIN of the individual on account of whose condition such benefits are paid.

The full text of existing legislation referenced above appears in the Appendix to this document. Specific sections referenced above are highlighted in yellow in Appendix. In addition to new legislation that will be required, certain elements in existing legislation may need to be modified to be consistent with PAS FSA legislation. That effort will require a careful review of the statutes in Appendix and all of Title 26 of the I.R.S. Code and any other related statutes. A knowledgeable tax attorney should undertake this important job, the details of which are beyond the scope of this paper.

Section 9. Policy Initiatives Regarding Persons with Disabilities

In this section, we discuss how the proposed FSA fits with President Barack Obama's plans for individuals with disabilities, the introduction of the ABLE Act of 2009 in both the House and the Senate, some of the challenges the PAS FSA may face, steps to be taken to gather support for a PAS FSA, and how to move the idea toward implementation.

The Administration's Plan for Individuals with Disabilities

The Obama administration developed a plan to "provide Americans with disabilities with the greatest possible access to the same opportunities as those without disabilities" (Obama & Biden, n.d., p. 1) by "(1) providing Americans with disabilities educational opportunities, (2) ending discrimination and promoting equality of opportunity for people with disabilities, (3) increasing employment rate of workers with disabilities, and (4) supporting independent, community-based living for Americans with disabilities." To the extent that this plan has been detailed, access and opportunities appear to be lynchpins to the effort.

Among the specific recommendations put forward by the administration, several are likely to impact directly on the potential for employment and the independence of persons with disabilities. Five of these are outlined below.

[36] Derived from the Health Insurance Portability and Accountability Act of 1996 > Title III Tax-Related Health Provisions > Subtitle C Long-term Care Services and Contracts > Part 1 General Provisions > § 323 (Reporting requirements).

Educating Employers about Tax Benefits

Passage of legislation establishing a PAS FSA is not likely to guarantee that PAS will be available to all employees who require them. As presented in Table 2, the rate of adoption of FSAs varies substantially across businesses. The most recent data indicate that less than one half of all workers are offered a FSA despite legislation for the health and dependent care FSAs that has been on the books for more than 2 decades. The rate at which businesses offer cafeteria plans and FSAs in particular differs depending on employer's size and, presumably, the characteristics of the workforce. The passage of legislation creating a new PAS FSA does not guarantee that employers will adopt it. As Barringer and Milkovich (1997) note, employers chose to offer flexible benefit plans because (1) employees request it, (2) because they would like to recruit and retain particular employees in their workforce, or (3) because a given benefit is the general practice in the field or industry in question.

Legislation takes time to be enacted. As noted earlier, the adoption FSA, passed in the late 1990s, has much lower employer-participation rates than the health and dependent care FSA account, which has been in place for over than a decade longer than the adoption FSA.

Finally, the number of potential beneficiaries may limit employer adoption of the PAS FSA. Because of low demand, business will feel little pressure to offer a PAS FSA. Unless the employer has a particular focus on recruiting employees with disabilities (e.g., the federal government mandate), employers may be slow to add the benefit to their cafeteria plans.

The Obama-Biden plan reasserts the executive branch's commitment to hiring workers with disabilities, encouraging private sector employers to use existing tax benefits to hire more workers with disabilities, and supporting small businesses owned by people with disabilities (Obama & Biden, n.d.). Adding an additional tax benefit for employees with disabilities and their employers can be expected to advance that effort.

Supporting Small Businesses Owned by People with Disabilities

The Obama-Biden (n.d.) plan reflects an intention to amend regulations under the Small Business Act to enable the federal government to include small businesses owned by people with disabilities in its contractual set-asides. Enabling individuals who are self-employed to take advantage of a PAS FSA may enhance the ability of individuals with disabilities to start or continue small businesses and to include themselves in the opportunity to set aside tax-free PAS FSA funds.

Establishing a National Commission on People with Disabilities, Employment, and Social Security

The Obama-Biden plan includes establishing a national commission to address and resolve some of the issues with federal programs for people with disabilities (Obama & Biden, n.d.). Specifically, the commission will address and resolve work disincentives associated with federal benefits programs, Social Security Disability Insurance, SSI, Medicare, and Medicaid and attempt to revamp the Ticket to Work Act to better provide transitions to work for individuals with disabilities. A PAS FSA is expected to help individuals with disabilities enter or remain in the workforce and decrease their reliance on federal assistance programs that pay for PAS. With representatives from the Departments of Social Security,

Labor, and Health Human Services as well as presidential and congressional appointees, the commission will be in a position to facilitate cross-agency involvement and promote the adoption of the legislation.

Promoting Work Flexibility for Workers with Disabilities and Family Caregivers

The Obama-Biden plan describes some workplace flexibility as "an appropriate—even an essential—accommodation" for workers with disabilities and for family caregivers (Obama & Biden, n.d., p. 5). As noted earlier, a PAS FSA may ease the strain on family caregivers by (1) enabling them to be paid for their services, or (2) enabling the individual with disabilities to pay another caregiver. With increased workplace flexibility, the family caregiver can focus on their own paying job rather than on outside commitments or the individual with disabilities.

Supporting the Community Choice Act and Direct Care Workers

The Obama-Biden (n.d.) plan acknowledges that the shortage of community direct-care attendants is related to low pay, limited or no benefits, and inflexible working hours. President Barack Obama and Vice President Joe Biden support Senator Tom Harkin's (D-IA) Community Choice Act of 2007, which enables individuals with disabilities to choose to live in the community rather than in a nursing home or institution, and the Fair Home Health Care Act, extending minimum wage and overtime protections to direct care attendants. In addition, the plan makes explicit the support of the administration for raising the minimum wage and providing all Americans with high-quality, affordable health insurance. These efforts on the part of the federal government might be expected to improve the lives of direct care attendants. If coupled with the increased flexibility that may be afforded by a PAS FSA, the workforce is expected to expand to meet the need.

Congressional Initiatives:

The Achieving a Better Life Experience (ABLE) Act of 2009

The Achieving a Better Life Experience Act of 2009 (ABLE Act) (H.R. 1205) was introduced in the House by Representatives Crenshaw (R-FL), Meek (D-FL), Kennedy (D-RI), and McMorris (R-WA) and in the Senate by Casey (D-PA), Hatch (R-UT), Dodd (D-CT), Brownback (R-KS), and Kennedy (D-MA). Both the Senate and the House versions of the bill count on a significant number of bipartisan cosponsors. The ABLE Act proposal creates ABLE accounts that allow individuals with disabilities and their families to save money, tax-free, for disability-related expenses. Modeled in part on the 529 college savings plans but unlike FSAs, contributions to ABLE accounts are not deductible on one's federal tax returns. Investments on an ABLE account grow tax-deferred. Distributions that come out of the accounts to pay for disability-related expenses are tax free. ABLE account funds allow for a variety of disability-related expenses that are adaptable to the needs of individuals with disabilities of different type and severity. Qualified disability expenses include education, housing, transportation, employment support, health, prevention, and wellness.

Funds in ABLE accounts are excluded from the means tests used by the government to grant certain disability-related benefits, such as SSI and Medicaid. In other words, the funds individuals with disabilities can expend through an ABLE account cannot be used to determine income eligibility for disability programs. An individual can have only one ABLE account. The lifetime cap is $500,000 in contributions to an ABLE account, although the investment can grow beyond that limit. ABLE accounts can be managed by individual beneficiaries themselves or legal guardians. Currently, relatives of

individuals with disabilities are confronted with expensive legal channels of establishing special needs trusts that provide funds for their needs. In addition to their costliness, rules governing such funds vary by state. ABLE accounts are federally regulated. Several disability rights groups, especially those focusing on children with disabilities, are pushing for the passage of the ABLE Act.

The Community Living Assistance Services and Supports (CLASS) Act of 2009

The Community Living Assistance Services and Supports Act of 2009 (CLASS Act) was introduced in both houses of Congress by Senator Edward Kennedy (D-MA) and Congressman Frank Pallone (D-NJ) on March 29, 2009 (S.697 and H.R. 1721). The CLASS Act proposes the creation of a national insurance program to be financed by payroll deductions to provide cash benefits to adults who become severely functionally impaired. This insurance would be financed through payroll deductions of $30.00 per month. Individuals may opt-out of enrollment, but they are automatically enrolled otherwise. Eligibility for these benefits would not affect eligibility to Social Security Disability Insurance (SSDI) or retirement benefits, while individuals who receive services under Medicaid would have their CLASS benefits used to offset the Medicaid costs to the states.

In order to qualify, individuals must be 18 or older and they must have contributed to the program for at least 5 years. The legislation would create a system with 2 insurance benefit tiers: Tier 1 benefits would pay $50 per day for eligible individuals who have two or more impairments on activities of daily living (ADLs), while a Tier 2 would afford a $100 per day benefit for individuals who have four or more impairments on ADLs or the equivalent cognitive impairments. Unused funds can be rolled over month to month, but not year to year. Funds can be used to purchase goods and services that promote independence and choice for individuals with functional impairments, including assistive technology, housing modification, personal assistance services and transportation.

Democrats who support this bill argue that it would be cost neutral, due to the program's funding via payroll deductions. Republicans claim that if premium deductions are fixed, the program would not be solvent as the long-term unfunded costs of the program would be enormous.

Section 10. Potential Challenges

Establishing and implementing a PAS FSA will require overcoming at least five potential challenges. First, FSAs and other forms of pre-tax employee benefits perpetuate disparities in the tax system. Second, the Treasury Department has concerns that allowing too much pre-tax compensation erodes the tax base and creates fiscal problems for the government. Third, due to many informal PAS providers that do not report their income, an individual may be limited in their choice for PAS providers. Fourth, even after 20 years of availability and minimal costs to them, many employers still do not offer FSA benefits to their employees. Finally, many eligible employees do not opt to participate, even when it is clear that the program offers cost savings to every participant. In the sections that follow, each issue is outlined along with ways in which the issue may be addressed.

Perpetuation of Disparities

In 1984, the Subcommittee on Taxation and Debt Management of the Committee on Finance in the U.S. Senate held a series of hearings on employee fringe benefits and their taxation and fairness implications. At the hearings, John E. Chapoton, the Assistant Secretary for Tax Policy at the U.S.

Department of the Treasury at the time, testified that nondiscrimination in the tax code was very important for providing tax benefits to a broad cross section of employees (U.S. Senate, 1985, p. 34). At the same hearings, Senator John H. Chafee (R-RI) testified on the danger of growing inequities between employees who receive tax-free benefits and those who must purchase services after taxes (U.S. Senate, 1985, p. 25).

There is some justification for these concerns. FSAs that allow employees to set aside funds before taxes are going to be more beneficial to employees in higher state and federal tax brackets (Scott, 2008). The PAS FSA account we propose is capped at $15,000 per year, significantly higher than the limits in the two other capped FSAs (dependent care at $5,000 and adoption assistance at $11,650). Although the health care FSA is not capped by law, employers have the option to (and do) cap it, often at $5,000 or less. The introduction of a FSA with a larger cap will add to, rather than reduce, the disparity in the IRS system. In addition, better paid employees typically have more access to fringe benefits and the ability to lower their taxes ("Frayed at the Fringe,"1984). However, some argue that fringe benefits can be used to make the workplace fairer by enabling a more diverse workforce (U.S. Senate, 1985). In addition, as noted previously, employed individuals with disabilities are much more likely to work in the secondary labor market and earn much less than those without disabilities. For individuals who earn low incomes, increasing the amount of take-home pay is a significant boon, allowing them to buy more and to develop assets.

Erosion of the Tax Base

Non-taxable benefits such as FSAs decrease taxable wages and erode the tax base ("Frayed at the Fringe," 1984). One of the objections to the 2004 FSA rollover bill was that it would reduce the amount of employee taxable income at a time of federal budget strain, requiring a tax or revenue increase that would be politically difficult to implement and unpopular (Weaver, 2004). Fox and Schaffer (1987) found that the Treasury Department regretted the passage of the 1978 law that allowed the creation of cafeteria benefit plans and FSAs. In 1984 the IRS attempted to push back against FSAs because of both the revenue loss problem and the lack of Treasury rules regulating coverage. As discussed in Section 2, the Treasury ultimately added the use-it–or-lose-it rule to FSAs, and Congress clarified the fringe benefits that could and could not be offered under cafeteria plans.

With a cap of $15,000, the proposed PAS FSA will add to the erosion of the tax base, although actual revenue losses may be small because of the relatively small number of potential beneficiaries compared to those using dependent care and health care FSAs. In addition, the increased labor-force participation that this FSA may afford is likely to offset any loss with additional payroll taxes.

Congress and the Treasury use the tax-preferred health and dependent care FSAs to create tax incentives to meet social or national goals. The revenue loss associated with tax-preferred status is justified by the argument that public funds would have to provide the service if employers did not. This argument was used to justify the inclusion of dependent care as a tax-preferred benefit (Sloan & Costello, 1989). One can argue that a PAS FSA would serve much the same function, allowing workers with disabilities a way to enter or return to work and limit or end dependence on public sources of income.

Compliance with Reporting Requirements of the Internal Revenue Service

Notwithstanding the law, the IRS estimated that the government loses $195,000,000,000 annually from the underground economy (i.e., employers and employees who do not report payroll or income to the IRS) (California Employment Development Department, n.d.). To participate in a PAS FSA, participants will be required to report the income paid for the caregiver and in some cases to contribute to Social Security and, perhaps, unemployment insurance. Therefore, caregivers will be required to file taxes. If paid caregivers resist providing their social security numbers so that wages are recorded, individuals with PAS needs would not be able to participate in the PAS FSA making it possible that individual's may not be able to use their caregiver of choice for a PAS if paying with an FSA.

However, both the individual with disabilities and the paid caregiver can reap significant benefits from reporting the payment and income. Obviously, the FSA participant will be able to use pre-tax dollars to pay for PAS. In addition, the participant will not fear that the failure to report and pay Social Security or Medicare, and, perhaps, unemployment insurance, will be discovered at some later point. At the same time, the paid caregiver will be building Social Security or Medicare and unemployment insurance benefits. In addition, the caregiver will have documented income to enable him to refinance or purchase a home.

Adoption of the Personal Assistance Services Flexible Spending Account by Employers

As noted earlier, the rate of adoption of FSAs varies substantially across businesses, depending on the employers' size and, presumably, the characteristics of the workforce. As President Obama and Vice President Biden (n.d.) suggest, employers will need to be educated on all of the tax benefits they can obtain by hiring and retaining individuals with disabilities.

Election of Personal Assistance Services Flexible Spending Account Participation by Employees

The take-up rate of health care FSAs among all eligible employees is 37 percent (see Table 2), with lower income, less educated workers are less likely to participate than higher-income, better-educated workers. Our interviews for this study suggest that lower income individuals—especially those who live paycheck to paycheck—cannot afford to set aside funds they may need, even though they would save in the long run. Although few actually forfeit money at the end of the FSA cycle, research also suggests that many fear the use-it-or-lose-it provision (Albritton, 2005). Economic analysis indicates that lower-income employees are better off forgoing the dependent care FSA in favor of the child care tax credit (Coe, 2002). The potential benefit of the PAS FSA needs to be weighed against the IRWE to determine the income levels at which one may be more beneficial than the other. To increase participation, benefits of FSAs to employees—especially low-income employees—must be documented and promoted.

Designing and implementing a PAS FSA that will increase the rate at which individuals with disabilities can enter and stay in the labor market will require the cooperative effort of individuals with disabilities and disability advocates, government agencies, legislators, employers, insurance agencies, and others. Toward this end, we will focus on identifying possibilities for consensus-based policies that

can work for both employees and employers and lay the groundwork for creating support for such policies among a diverse range of key stakeholders. This effort will involve (1) convening "listening sessions" with key informants to identify and address concerns that may develop in response to this proposal and (2) strategizing with representatives of stakeholder agencies to identify potential supporters and move the process forward.

Section 11. Conclusion

In this white paper, we explored the extent to which a PAS FSA may enable people with disabilities to keep or find and retain viable employment, leave the public welfare rolls, and build assets that will make their lives more comfortable and complete. The need for PAS is keeping Americans with disabilities out of the workplace, and the creation of a FSA to cover these services will expand access to employment for workers with disabilities. A FSA PAS will also affect other stakeholders, including those who provide informal PAS to friends and family members, the workers who provide professional PAS, the federal government, and the employers who would be able to add this FSA to their cafeteria benefits plans.

The Need for Personal Assistance Services

Decades of activism have changed the perception of the competence and capability of persons with disabilities; a strong movement has voiced opposition to the medicalization of chronic illness and disability, which disenfranchises this large segment of society (Caplan, 1988). It is now widely acknowledged that persons with disabilities can and should live independently in their communities (McDonald & Oxford, n.d.). Despite this, barriers remain that keep persons with disabilities out of the workplace. Working-age Americans with disabilities are far less likely to be employed than their peers without disabilities (U.S. Bureau of Labor Statistics, 2009), and a household with at least one member with a disability has a much lower median income than that of a household without a member with a disability (U.S. Census Bureau, 2000). Nearly 6,000,000 working-age people in the United States need PAS to live independently in their communities (Adams et al., 2008; Nosek, 1991) and perhaps 1,000,000 of these potential workers are kept out of the workforce because they cannot afford or access the necessary PAS (Hinton, 2003; Livermore et al., 2000).

The Structure of the Proposed Personal Assistance Services Flexible Spending Accounts

In this white paper, we propose a new FSA to cover the cost of non-medical PAS for workers who require these services to join the workforce and contribute to the economy and their communities. Currently, there are two main FSAs offered under many employer cafeteria plans: the health care FSA, which covers medical, dental, and vision services including deductibles and medication, and the dependent care FSA, which covers work-related caregiving services for the dependents of a worker (U.S. Department of the Treasury, Internal Revenue Service, 2008). Neither covers the cost of non-medical PAS and neither provides help to workers with disabilities who require these services to work and live in their community. The proposed FSA would allow employees to set aside pre-tax money to fund PAS. Employers would be able to choose whether to implement this FSA, which would have an annual cap of $15,000.

How Workers with Disabilities Will Be Affected

An individual would need to make a salary of at least $40,000 to roughly match the public benefits a family of three may have been receiving (as estimated by a description of a well-researched fictional family), including health insurance, health care expenses, public PAS benefits, and various state and federal income taxes. If able to contribute $7,500 to a PAS FSA, the individual would save almost $1,200 in income and other taxes. Currently this individual could recoup some expenses using the IRWE income tax deduction, but with a PAS FSA the individual would be able to purchase 20 to 40 percent more services using pre-tax dollars.

One potential objection to this proposal is the disincentive created by the loss of public health-care benefits when persons with disabilities enter the workplace. We included a descriptive analysis to simulate the effect of additional post-tax income that would be available to people with disabilities if a PAS FSA were available. We used the results to explore whether or not the disincentive of lost benefits would outweigh the benefits of returning to work. The findings indicate that an increase in post-tax income from the availability of a PAS FSA could lead to a slight increase in the percentage of people with disabilities who return to work.

How Other Stakeholders Will Be Affected

A PAS FSA will impact other stakeholders, including providers, the federal government, and employers.

Personal Assistance Services Providers

Both formal and informal PAS providers could be positively affected by the proposed PAS FSA. An estimated 44,400,000 Americans provide informal PAS to family members and friends, including assisting with bathing, eating, preparing meals, housekeeping, shopping, managing medications, and other activities of daily living (Feinberg et al., 2004). These informal caregivers can lose wages, Social Security, and pension benefits if the caregiving takes them away from their paid employment. They also report emotional stress and physical or mental health problems as a result of caregiving, and they have higher rates of depression (Foster et al., 2005). Helping some persons with disabilities gain access to the funds to pay for formal PAS could take some of this pressure off of informal caregivers, improving their emotional and physical health and freeing them to work and earn assets themselves.

According to BLS estimates, approximately 595,000 paid personal and home care aides worked in 2007. These are typically agency-based positions with low pay, low skills requirements, and high emotional demands (U.S. Bureau of Labor Statistics, 2007). A PAS FSA could increase employment for these workers, enable them to form an ongoing relationship with individual clients outside of an agency-based model, and improve their asset development.

Federal Government

In this paper, we estimate that a married individual with one child would save the government $19,380 by forfeiting SSI or SSDI benefits and returning to work. In addition, this individual may use fewer non-PAS Medicaid expenses (Hashemi et al., 2003). The government also would collect FICA, FUTA, and income taxes, estimated at around $8,000 total. However, if an already-employed person began to withhold taxable income for the new FSA, the government would lose money in the amount of

the employee's and the employer's FICA and income taxes for the amount set aside for the PAS FSA. However, revenue losses are a potential outcome for any kind of tax deduction and are considered appropriate when Congress and the Treasury use tax incentives to meet social or national goals. Additionally, compared to the numbers using health care or dependent care FSAs, a relatively small number of potential beneficiaries will use PAS FSAs.

Employers

With the proposed PAS FSA, employers could hire skilled persons with disabilities and still reduce their payroll taxes. For the employers, the only negative to adding another FSA to an existing cafeteria plan may be an increase in the administrative costs to run the plan. However, estimates indicate that these costs are very low: approximately $100 dollars per account per year (Employee Benefit Research Institute, 2008).

Alternatives to Personal Assistance Services Flexible Spending Accounts

Alternatives to creating a new FSA exist, but a PAS FSA is superior to the alternatives on multiple merits. First, HSAs could be modified to cover PAS that are not medical in nature. However, even if covered services were expanded to include PAS, individuals may need to choose between covering necessary health care or PAS expenses. Also, using HSAs perpetuates the stigma of the medical model that disability rights activists have worked to overcome. A second alternative is the IRWE income tax deduction. This only allows tax relief for part of the PAS expenses and forces individuals to wait for tax return season to recoup losses. Additionally, a significant percentage of eligible individuals do not file taxes or claim the credit to which they are entitled (Holt, 2006).

Finally, the existing dependent care FSA could be broadened to include PAS for the insured individual as well as his or her dependents. This alternative is more feasible than the others and is closer in form to the PAS FSA proposed in this paper. Currently, the dependent care FSA has a very low cap of $5,000 annually, which would need to be increased to allow individuals to cover themselves and any dependents. Also, the name of the FSA would need to be modified to reflect the change. Two benefits characterize this alternative: First, because this FSA benefit already exists, no new, costly, and potentially controversial legislation would be needed. Second, this FSA has already been adopted by many firms, which is an important consideration because new cafeteria benefits are slowly adopted by businesses.

Moving Forward to Help Americans with Disabilities Enter or Remain in the Labor Force

Helping Americans with disabilities enter or remain in the job market requires collaboration and cooperation with multiple stakeholders to overcome challenges. Stakeholders must work together to ensure that existing laws do not impede the formation of a new FSA, identify and rally potential supporters, and define particulars of the new FSA such as eligibility, covered services, and other practical issues. In addition, stakeholders must address potential concerns, such as how to ensure that informal and formal caretakers comply with IRS reporting requirements, how to publicize the new FSA to employers and employees alike, and to how make certain that these cafeteria benefits are widely available to fight inequity. Designing and implementing a PAS FSA will enable individuals with disabilities

to continue to move away from a medical model that focuses on limitations and restrictions and toward a model that focuses instead on strengths and possibilities.

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