

**Disability  
Literacy,  
Diabetes  
and Social  
Security  
Disability  
Insurance**

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## Abstract

Disability literacy is the ability to obtain and understand information regarding health, finances and resources to adapt to, anticipate and overcome challenges resulting from a chronic illness and/or disability. The significant health impact and costs of diabetes in the U.S. makes it an important area of concentration for disability literacy. In addition, the relevance of disability literacy among individuals of color with diabetes is underscored by the rate of diabetes-related disability, prevalence of diabetes among people of color, and the impact of disability benefits within minority populations.

- People with diabetes, in general, report rates of disability that are significantly higher than those reported by the general U.S. population.
- The prevalence of diabetes, both diagnosed and undiagnosed, in non-Hispanic blacks and Mexican-Americans is about 70 to 80 percent higher than that of non-Hispanic whites.<sup>1</sup>
- Social Security disability benefits, administered by the Social Security Administration (SSA), are important sources of income security for many people of color.<sup>2</sup>

## Diabetes and Disability Literacy

The Centers for Disease Control and Prevention (CDC) estimates that 25.6 million, or 11.3 percent of all Americans age 20 and older, have diabetes. Many of these individuals work, manage and treat their diabetes and diabetes-related disabilities, have a family support network and maintain a relatively financially secure and healthy lifestyle. However, some move further down the spectrum—experiencing a severe, long-term disability. Whether through amputation, blindness or kidney failure—it can be a devastating experience physically, mentally, emotionally and financially.

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1 National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). *New Survey Results Show Huge Burden of Diabetes; Study Includes Sensitive Test of Blood Glucose Abnormalities*, January 2009. <http://minorityhealth.hhs.gov/templates/content.aspx?ID=7435>

2 Social Security Administration, *Social Security Is Important To African Americans*, February 2013. <http://www.socialsecurity.gov/pressoffice/factsheets/africanamer.htm>

Increasing disability literacy empowers individuals and their caregivers to access available resources and make informed decisions to safeguard and improve their financial and health status. Research shows high levels of health literacy correlate to increases in self-efficacy, behavior modification, and positive health outcomes. This paper reviews the U.S. government's definition of health literacy and describes how disability literacy has the potential to similarly correlate with positive health and financial outcomes. It provides a definition of disability literacy, qualitative and quantitative research on the experiences of individuals with one or more severe disabilities (as defined by their inability to work), and provides supports to increase disability literacy, enhancing patient outcomes.

## **Health Literacy Definition**

The U.S. Department of Health and Human Services defines “health literacy” as the ability to obtain, process, and understand basic healthcare information and services to make appropriate health decisions. Limited health literacy affects people's ability to search for and use health information, adopt healthy behaviors, and act on important public health alerts. Limited health literacy also is associated with worse health outcomes and higher costs.<sup>3</sup>

## **Current Status of U.S. Health Literacy Levels**

Research shows that currently available health information is too difficult for average Americans to use to make health decisions.<sup>4</sup> Even people with strong literacy skills can face health literacy challenges, such as when:

- They are diagnosed with a serious illness such as diabetes and are scared or confused.
- They have complex conditions such as diabetes that require complicated self-care.

<sup>3</sup> Berkman ND, DeWalt DA, Pignone MP, Sheridan SL, Lohr KN, Lux L, Sutton SF, Swinson T, Bonito AJ. Literacy and Health Outcomes. Evidence Report/Technology Assessment No. 87. AHRQ Publication No. 04-E007-2. Rockville, MD: Agency for Healthcare Research and Quality. January 2004. <http://archive.ahrq.gov/downloads/pub/evidence/pdf/literacy/literacy.pdf>

<sup>4</sup> U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. *America's Health Literacy: Why We Need Accessible Health Information*. <http://www.health.gov/communication/literacy/issuebrief/>

- They are not familiar with medical terms or how their bodies work.
- They have to interpret numbers or risks to make a healthcare decision.

### Individuals who must quit working due to diabetes face all or many of these situations.

- Individuals with diabetes face a much higher risk of disability—in some cases up to 80 percent higher—than those without the condition.<sup>5</sup>
- Diabetes is the leading cause of kidney failure, adult-onset blindness, lower limb amputations, significant cause of heart disease and stroke, high blood pressure and nerve damage.
- In 2007, 445,000 cases of unemployment disability were caused by diabetes.<sup>6</sup>

### Disability Literacy Definition

This paper adapts established benchmarks of financial<sup>7</sup> and health literacy to address the unique needs of individuals with or at risk of disability (everyone is at risk of disability). It defines “disability literacy” as the ability to obtain, process and understand basic information regarding finances, healthcare and available resources needed to prepare for and manage physical, financial, emotional and mental challenges resulting from a disability.

### Social Security Disability Insurance (SSDI) Literacy

SSDI literacy is a component of disability literacy. SSDI literacy is the degree to which an individual has the skill set and knowledge to make informed decisions regarding SSDI and can confidently take action to maximize all available resources to improve his or

<sup>5</sup> Wong, E., Backholer, K., Gearon, E., Harding, J., Freak-Poli, R., Stevenson, C., Peeters, A. Diabetes and risk of physical disability in adults: a systematic review and meta-analysis. *The Lancet Diabetes & Endocrinology*, Volume 1, Issue 2, Pages 106 - 114, October 2013. doi:10.1016/S2213-8587(13)70046-9

<sup>6</sup> American Diabetes Association, *Direct and Indirect Costs of Diabetes in the United States*, January 2008. [http://www.house.gov/degette/diabetes/docs/Costs.fs\\_Final.pdf](http://www.house.gov/degette/diabetes/docs/Costs.fs_Final.pdf)

<sup>7</sup> The Institute for Financial Literacy uses the following risk management and insurance benchmarks to measure literacy levels. Can an individual:

- Differentiate among the types of insurance products?
- Understand their insurance needs?
- Comprehend the implications of being insured or uninsured?
- Evaluate the effectiveness of risk management tools in protecting against financial loss?
- Assess their risk tolerance level?
- Use risk tolerance levels in developing risk management strategies?

*National Standards for Adult Financial Literacy Education*, October 2007. <https://financiallit.org/wordpress/wp-content/uploads/2013/06/NationalStandardsBenchmarks.pdf>

her health and financial well-being before and/or after work is no longer possible due to disability. Many individuals are unaware that they may qualify for SSDI and Medicare benefits. Some falsely believe common myths, for example, that a disability must be permanent or that their income must fall below a certain level. According to the Urban Institute<sup>8</sup>, fewer than half (47 percent) of adults who meet the disability criteria receive public disability benefits at some point between ages 51 and 64.

## **Disability Literacy (DL) Basics**

Increasing a person with diabetes' knowledge and understanding of the following five content areas can result in improved disability literacy.

1. Long-term disability insurance (LTD)
2. Social Security programs/SSDI literacy
3. Personal finance/Disability life planning
4. Healthcare
5. Government and community resources

### **DL Basic 1 - Know your LTD options and individual plan requirements.**

According to the Social Security Administration, just over 1 in 4 of today's 20-year-olds will become disabled before they retire, but 69 percent of the private sector workforce has no LTD insurance. LTD policies vary in their definitions of disability, benefit rates, benefit periods, premiums and other factors.

Most long-term disability policies require individuals to file for Social Security Disability Insurance (SSDI). Complying with this requirement could help protect an individual's ability to receive LTD income.

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<sup>8</sup> Johnson, R.W., Favreault, M.M., Mommaerts, C. Disability Just Before Retirement Often Leads to Poverty. *Older Americans Economic Security, The Retirement Policy Program*. The Urban Institute. No. 22. January 2010. <http://www.urban.org/publications/412009.html>

## **DL Basic 2 - Understand Social Security programs and benefits, how they interact, eligibility, the application process and the right to representation.**

More than 152 million workers are insured for federal benefits through the Old-Age and Survivors Insurance (OASI/retirement) and Social Security Disability Insurance (SSDI) trust funds. The SSA also administers the means-based Supplemental Security Income (SSI) program.

Social Security Disability Insurance (SSDI) is a payroll tax-funded, federal insurance program. The SSA pays only for total disability. No SSDI benefits are payable for partial disability or for short-term disability.

SSDI benefits include:

- Regular monthly income with annual cost-of-living increases.
- Access to Medicare, including Part D, 24 months after date of entitlement to SSDI cash benefits.
- Possible extension of COBRA benefits an additional 11 months.
- Earnings record “freeze,” which could preserve the value of retirement benefits. Because the years in which SSDI benefits are collected are not counted when computing future benefits, Social Security retirement benefits may be higher than if earnings were averaged over a greater number of years.
- Dependent benefits for children under age 18.
- Opportunities to return to work while still receiving disability benefits.

To be eligible for SSDI, a diabetic patient must:

- Be under retirement age (65-67).
- Have enough work credits to be currently and fully insured. Usually, if an individual has worked for five out of the last 10 years, he/she will have the required 20 credits.
- Not be able to do previous work.

- Cannot adjust to other work because of a medical condition(s).
- Have a disability that has lasted or is expected to last for at least one year or result in death.

One step in the SSA's disability review process involves determining if a condition meets or equals a medical listing. SSA's Listing of Impairments describes medical conditions that are so severe the SSA presumes any person who has a medical condition(s) that satisfies the criteria of a listing is unable to perform any gainful activity and, therefore, is disabled. According to SSA, the listings are special rules that help them identify claims that should clearly be allowed for Social Security disability benefits.

**In 2011, the SSA removed endocrine disorders from its Listing of Impairments. SSA adjudicators evaluate diabetes and other endocrine disorders under listings for other body systems. For example:**

- **Amputations can be evaluated under musculoskeletal disorders.**
- **Diabetic nephropathy can be evaluated under genitourinary listings.**
- **Peripheral neuropathies can be evaluated under neurological disorders.**

**SSA considers how a condition affects a person's ability to do any past relevant work or any other work, considering their age, education and previous work experience, in determining disability.**

## **SSDI and People of Color**

**The SSA reports<sup>9</sup>:**

- **African-Americans have lower life expectancy and higher disability rates before age 65 as compared to whites and are more likely to be eligible for and receive Social Security disability and survivor benefits.**

<sup>9</sup> Social Security Administration, *Social Security Is Important To African Americans*, February 2013. <http://www.socialsecurity.gov/pressoffice/factsheets/africanamer.htm>

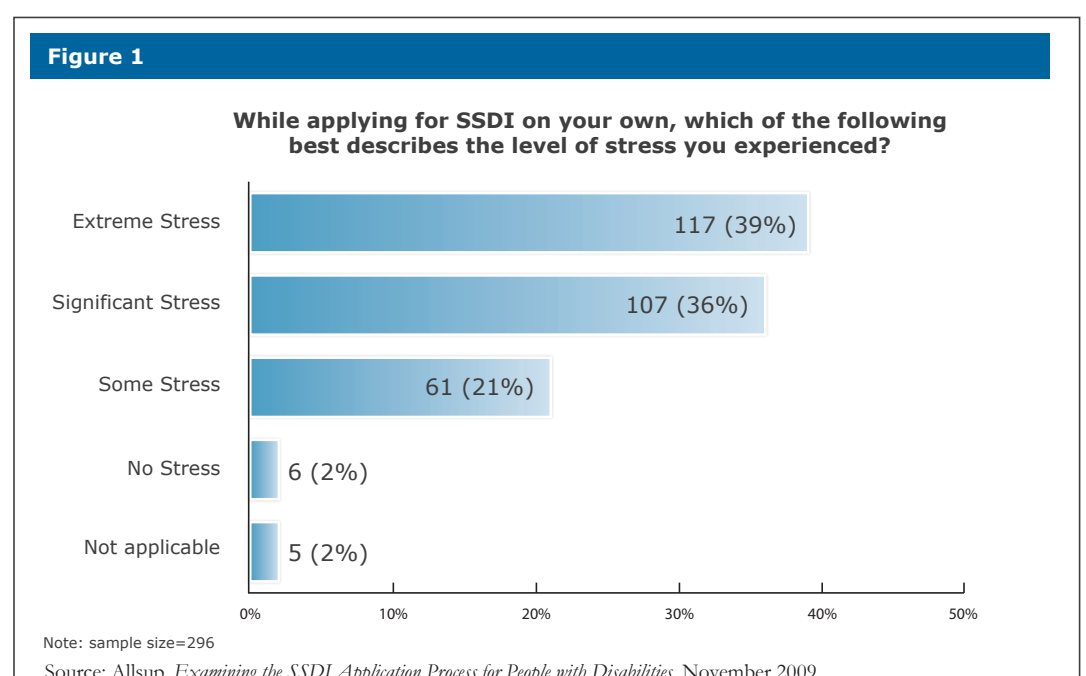
- In the U.S., disabled workers are more likely to be black or Hispanic.
- African-Americans benefit from disability insurance. In 2011, 12.6 percent of the population was African-American; however, 19 percent of disabled workers receiving benefits were African-American.
- Under SSA's system, lower-wage earners typically receive a higher percentage benefit than higher-wage earners do; this is because benefits are relatively low and lower earners end up receiving a higher percentage of their former income. This means the value of SSDI benefits may be especially significant because the income-replacement value is closer to their actual income while working. However, the average SSDI benefit is still only approximately \$1,132.
- African-Americans receiving benefits also are helped by the cost-of-living adjustment applied to Social Security benefits. This adjustment, usually effective in January, accounts for inflation.

While SSDI is an important resource for former workers, the application process can be confusing, stressful and frustrating. More than two-thirds of initial SSDI applications are denied.

**Among individuals with diabetes, the rate of denial is even higher—81 percent.<sup>10</sup>**

A 2009 nationwide survey of SSDI applicants revealed the majority faced grave setbacks and wished they had known from the start that expert representation to assist them was available.<sup>11</sup>

- Three-fourths said the level of stress they experienced while applying for SSDI benefits was either “extreme” or “significant” (Fig. 1).



<sup>10</sup> Social Security Administration, Office of the Inspector General. *Disability Impairments on Cases Most Frequently Denied by Disability Determination Services and Subsequently Allowed by Administrative Law Judges*, August 2010. <http://oig.ssa.gov/sites/default/files/audit/full/pdf/A-07-09-19083.pdf>

<sup>11</sup> Allsup. *Examining the SSDI Application Process for People with Disabilities*, November 2009, <http://www.allsup.com/media/files/allsup-claimant-survey-results-final.pdf>



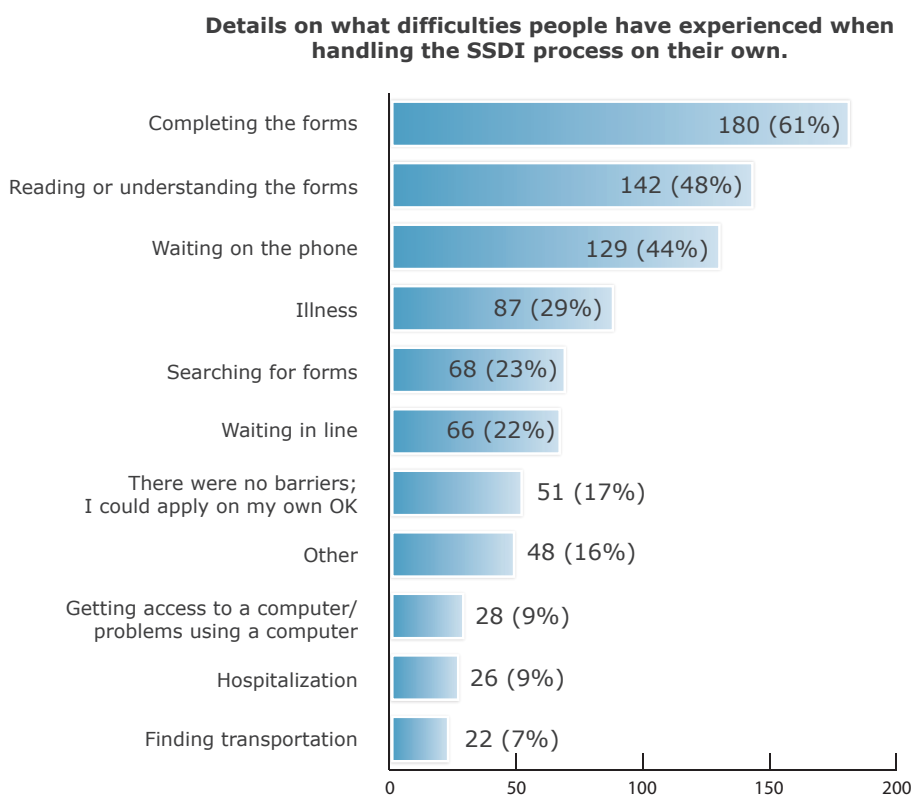
- Nearly 80 percent of respondents reported facing “barriers to handling the SSDI process on [their] own,” including problems with understanding and completing the necessary forms (Fig. 2).

In addition, almost 90 percent of applicants said they faced negative repercussions while waiting for their SSDI award (Fig. 3). These included:

- Stress on family – 63 percent
- Worsening illness – 53 percent
- Draining of retirement/savings – 35 percent
- Lost health insurance – 24 percent
- Missed mortgage payments – 14 percent
- Foreclosure – 6 percent
- Bankruptcy – 5 percent

A 2010 SSA Office of the Inspector General report concluded that in the cases they reviewed, professional representation at the early stages of the SSDI application process could have saved some claimants about 500 days in receiving an allowance decision. (Fig. 4)

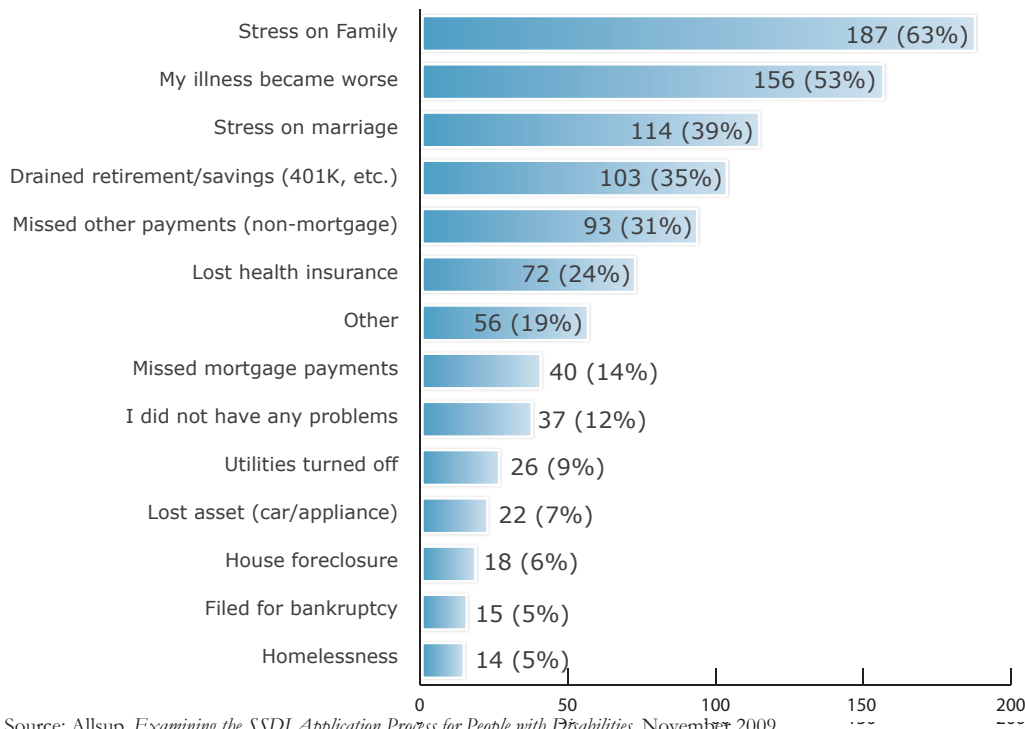
Figure 2



Source: Allsup. *Examining the SSDI Application Process for People with Disabilities*, November 2009.

Figure 3

**Did you face repercussions during the time period before you received your SSDI award, and if so, what were they? (Please select all that apply.)**



Source: Allsup. *Examining the SSDI Application Process for People with Disabilities*, November 2009.

Figure 4



“If claimants...had representatives earlier in the disability process, some of them may have received an allowance decision at the DDS level, saving them time and SSA money.

First, the claimants may not have had to go to the hearing level if they had representatives to assist them with completing SSA’s forms and providing the necessary evidence at the DDS level.

This could have saved some claimants about 500 days in receiving an allowance decision.”

**Fig. 5**

Four Impairments Most Frequently Denied by DDSs and Subsequently Allowed at the Hearing Level

Impairment	Number of DDS Denials	DDS Denial Rate	Number of Hearing Level Allowances	Hearing Level Allowance Rate
Disorders of Back	744,602	78%	238,903	70%
Osteoarthritis and Allied Disorders	204,652	58%	61,118	70%
<b>Diabetes Mellitus</b>	<b>165,411</b>	<b>81%</b>	<b>38,174</b>	<b>67%</b>
Disorders of Muscle, Ligament, and Fascia	138,905	80%	34,693	65%

Source: Social Security Administration, Office of the Inspector General. Disability Impairments on Cases Most Frequently Denied by Disability Determination Services and Subsequently Allowed by Administrative Law Judges, August 2010. <http://oig.ssa.gov/sites/default/files/audit/full/pdf/A-07-09-19083.pdf>

## Diabetes Patients and SSDI

- Individuals with diabetes are among those most often denied benefits at the initial application level, yet subsequently awarded benefits at the hearing level (Fig. 5).

- Loss of health insurance negatively impacts access to care and adherence to treatment. Some people simply cannot afford to see a doctor or purchase prescriptions without insurance. Patients are eligible for Medicare, including prescription coverage, 24 months after they begin receiving cash SSDI benefits.
- To qualify for SSDI, you must be considered totally disabled and unable to engage in substantial gainful activity (defined as making more than \$1,040.00 per month). Many people with diabetes are unable to work full time, but can manage part-time or occasional employment.

### DL Basic 3 – Understand the financial implications of your disability and your options for managing your finances and healthcare needs.

Prior to a permanent disability, less than 40 percent of American adults have any kind of emergency savings fund to use in the event of a financial downfall.<sup>12</sup> When a person is forced to stop working because of a disability, the sudden decrease in income coupled with increased healthcare costs can create immediate financial crises and long-term debt and stress.

**Diabetes-related complications that often preclude the ability to work include peripheral neuropathy amputation, blindness, vascular disease and renal failure.**

<sup>12</sup> The National Foundation for Credit Counseling. *The 2011 Consumer Financial Literacy Survey Final Report*, March 2011. [http://www.nfcc.org/newsroom/FinancialLiteracy/files2011/NECC\\_2011Financial%20LiteracySurvey\\_FINALREPORT\\_033011.pdf](http://www.nfcc.org/newsroom/FinancialLiteracy/files2011/NECC_2011Financial%20LiteracySurvey_FINALREPORT_033011.pdf)

Most Americans don't have enough savings to last 31.2 months—the duration of the average long-term disability claim.<sup>13</sup> Stress over financial concerns often contributes to poor health.

Many people turn to retirement savings following a disability, which erodes their ability to reach long-term financial security.

The need to plan for a declining physical and mental condition could mean creating a living will and an advance directive for healthcare. Considerations for long-term care, including employing personal assistance, relying on family and caregivers, and setting up a power of attorney, are best done before a crisis. Writing a will, establishing a trust for dependents and other decisions also should be considered.

### **Diabetes Patients and Financial Considerations**

- In 2007, diabetes accounted for 15 million work days absent, 120 million work days with reduced performance, 6 million reduced productivity days for those not in the workforce, with an additional 107 million work days lost due to unemployment disability attributed to diabetes.<sup>14</sup>
- People with diabetes spend 2.3 times more on medical expenses than those without—an average of \$13,700 a year per person, about \$7,900 of which is directly attributed to diabetes.<sup>15</sup>

**DL Basic 4 – Know your health insurance coverage options and how much they will cost, as well as options for mitigating healthcare costs.**

A survey of SSDI applicants showed that 24 percent lost health insurance while awaiting their award (Fig. 4).

Being aware of the full range of options regarding healthcare needs and costs is key to being disability literate. For example, healthcare professionals are finding that by helping their insured

<sup>13</sup> Council for Disability Awareness, [http://www.disabilitycanhappen.org/chances\\_disability/](http://www.disabilitycanhappen.org/chances_disability/)

<sup>14</sup> American Diabetes Association, *Direct and Indirect Costs of Diabetes in the United States*, January 2008. [http://www.house.gov/degette/diabetes/docs/Costs.fs\\_Final.pdf](http://www.house.gov/degette/diabetes/docs/Costs.fs_Final.pdf)

<sup>15</sup> American Diabetes Association. *American Diabetes Association Releases New Research Estimating Annual Cost of Diabetes at \$245 Billion*, March 2013. <http://www.diabetes.org/for-media/2013/annual-costs-of-diabetes-2013.html>

patients fully understand the benefits of filing for SSDI with a representative, they are less likely to become uninsured or underinsured at a later time, enhancing continuity of care and patient outcomes.

Additional areas to explore include:

- COBRA coverage
- Medicare coverage/ensuring enrollment in the best available plan to meet individual needs
- Drug company assistance programs
- State pharmaceutical assistance programs
- Generic drugs
- Negotiating lower healthcare costs
- Finding local healthcare resources

### **DL Basic 5 – Know your full range of assistance resources and how to access them and/or get help accessing them.**

Many people are not aware of available resources and programs provided at local, state and national levels designed to support people with disabilities. Or, if they are aware of the programs, they are unsure about eligibility requirements or intimidated or unclear about the application process. Gaining familiarity with the types of resources available and application assistance is part of disability literacy. Assistance typically falls under these general areas:

- Healthcare
- Cash
- Housing
- Utilities
- Food
- Other (e.g., transportation)

### **Conclusion**

Disability literacy helps individuals with diabetes understand their full range of options and identify the resources available to them before and when a crisis changes their lives. Diabetes disproportionately affects communities of color, resulting in

higher rates of diabetes-related disability and unemployment due to disability in these communities.

Social Security Disability Insurance is an important resource for individuals who cannot continue working due to disability. For a number of reasons—disparity of wages, differing life expectancy and rates of disability, and SSA’s progressive payment system (lower-wage earners receive a higher percentage of former income compared to higher-wage earners)—SSDI is a significant income support for former workers of color.

Many workers rely on their human resources department while working, turning to this support when making important health and financial decisions.

Because workers’ focus may be on their employers’ providers (i.e., health insurance, 401(k), etc.) and their personal earnings, they don’t realize the multitude of options available when they lose these key supports. With a lifelong disease such as diabetes, the crisis often is compounded by lost employment, lost income and lost human resources support. This can leave the diabetes patient floundering, disoriented and frustrated.

By increasing disability literacy:

- Diabetes patients can plan for disability earlier in their working career with steps such as purchasing long-term disability insurance, better understanding their healthcare options (such as COBRA coverage), and saving for future needs.
- Diabetes patients can learn about the tax-funded programs and benefits they are paying for/paid for during their working years, and programs offered through their local, state and federal governments.
- Diabetes patients will be empowered to have discussions with their physicians about their ability to work and enlist them as advocates.
- Diabetes patients can be proactive in determining their next steps if they must stop working.
- Diabetes patients can access help quickly by knowing their options and taking advantage of available resources.