

**Increasing
Disability
Literacy to
Enhance
MS Patient
Outcomes**

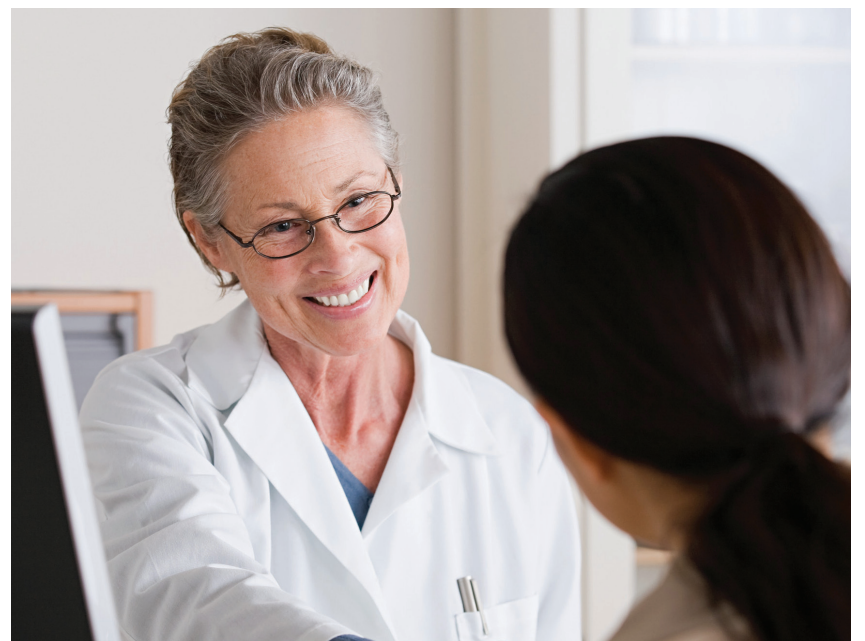
Summary

Experts believe that 250,000 to 350,000 people in the U.S. have been diagnosed with multiple sclerosis (MS).¹ MS patients are among the more than 50 million people living in the U.S. with some type of disability. Many of these individuals work, manage and treat their MS and/or disability, 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 injury, illness or a degenerative condition—it can be a devastating experience physically, mentally, emotionally and financially.

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 outcomes as well as 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



¹ National Institute of Neurological Disorders and Stroke, http://www.ninds.nih.gov/disorders/multiple_sclerosis/detail_multiple_sclerosis.htm

on important public health alerts. Limited health literacy also is associated with worse health outcomes and higher costs.²

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.³ Even people with strong literacy skills can face health literacy challenges, such as when:

- They are diagnosed with a serious illness such as MS and are scared or confused.
- They have complex conditions such as MS that require complicated self-care.
- 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 a disability face all or many of these situations.

- MS is associated with high rates of unemployment.
- Data from a 2008 review of the North American Research Committee on Multiple Sclerosis-MS Patient Registry suggests that close to 60 percent of MS patients age 64 or under (mean age 47 years) are unemployed.⁴
- The loss of employment brings detrimental consequences to [MS] patients and families with respect to short-term and long-term economic, psychosocial and healthcare utilization domains.⁵

Disability Literacy Definition

This paper adapts established benchmarks of financial⁶ 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

2 Berkman, N. D., DeWalt, D. A., Pignone, M. P., Sheridan, S. L., Lohr, K. N., Lux, L., et al. (2004). Literacy and health outcomes. *AHRQ Publication No. 04-E007-2* Rockville, MD: Agency for Healthcare Research and Quality.

3 *America's Health Literacy: Why We Need Accessible Health Information*, <http://www.health.gov/communication/literacy/issuebrief/>

4 Julian, L., Vella, L., Vollmer, T., Hadjimichael, O., Mohr D. (2008). Employment in multiple sclerosis Exiting and re-entering the work force. *J Neurol*; 255(9): 1354–1360.

5 McCabe M.P., De Judicibus M. (2003). Multiple sclerosis and economic well-being: role of health, age, and duration of illness. *J Clin Psychol Med Settings*;10:139–147.

6 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, <http://www.financiallit.org/resources/standards.aspx#D>

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 is a component of Disability Literacy. SSDI Literacy is the degree to which an individual has the skill sets and knowledge to make informed decisions regarding SSDI and can confidently take action to maximize all available resources to improve his or 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 Institute⁷, 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 an individual's knowledge and understanding of these five content areas will increase their 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 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

⁷ Johnson, R.W., Favreault, M.M., Mommaerts, C. (2010) Disability Just Before Retirement Often Leads to Poverty. *Older Americans Economic Security, The Retirement Policy Program*. The Urban Institute. No. 22.

could help protect an individual's ability to receive LTD income.

Common LTD policy exclusions that could impact MS patients include:

- Self-reported symptoms, such as headaches, pain and fatigue.
- Pre-existing conditions.
- Depression and/or affective disorders (time limitations)

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

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

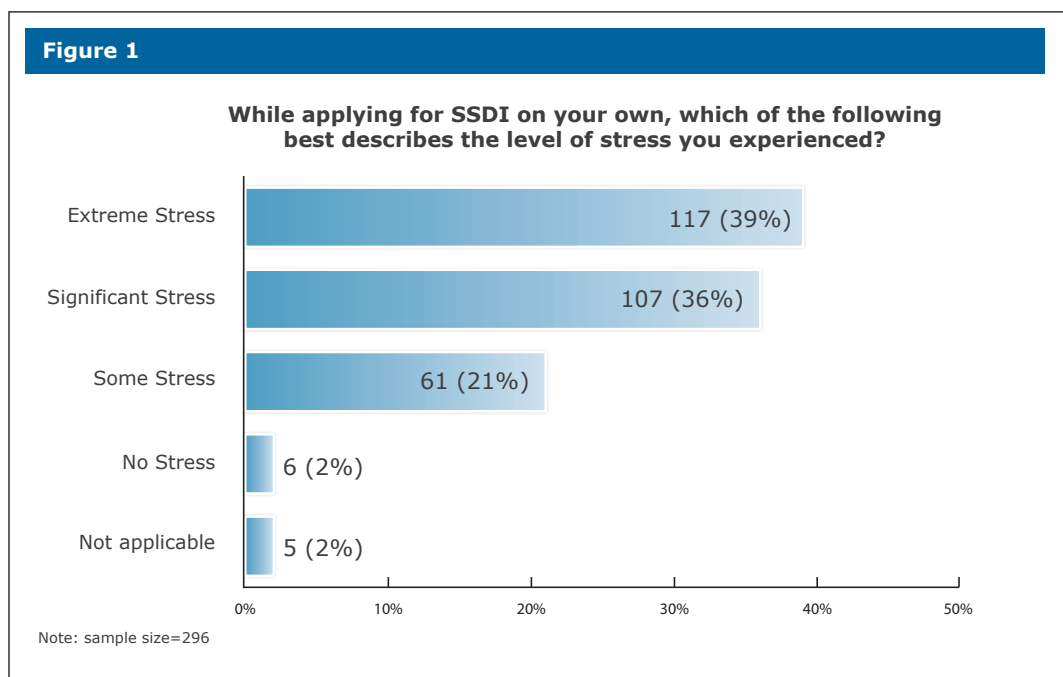
Social Security Disability Insurance (SSDI) is a payroll tax-funded, federal insurance program. The SSA pays only for total disability. No SSDI benefits are payable for partial disability or for short-term disability.

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 protect higher retirement benefits; avoid having low or zero-earnings years (due to disability) averaged into your retirement benefit calculation.
- Dependent benefits for children under age 18.
- Opportunities to return to work while still receiving disability benefits.

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.⁸

8 *Examining the SSDI Application Process for People with Disabilities, 2009*, Allsup. <http://www.allsup.com/portals/4/allsup-claimant-survey-results-final.pdf>



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

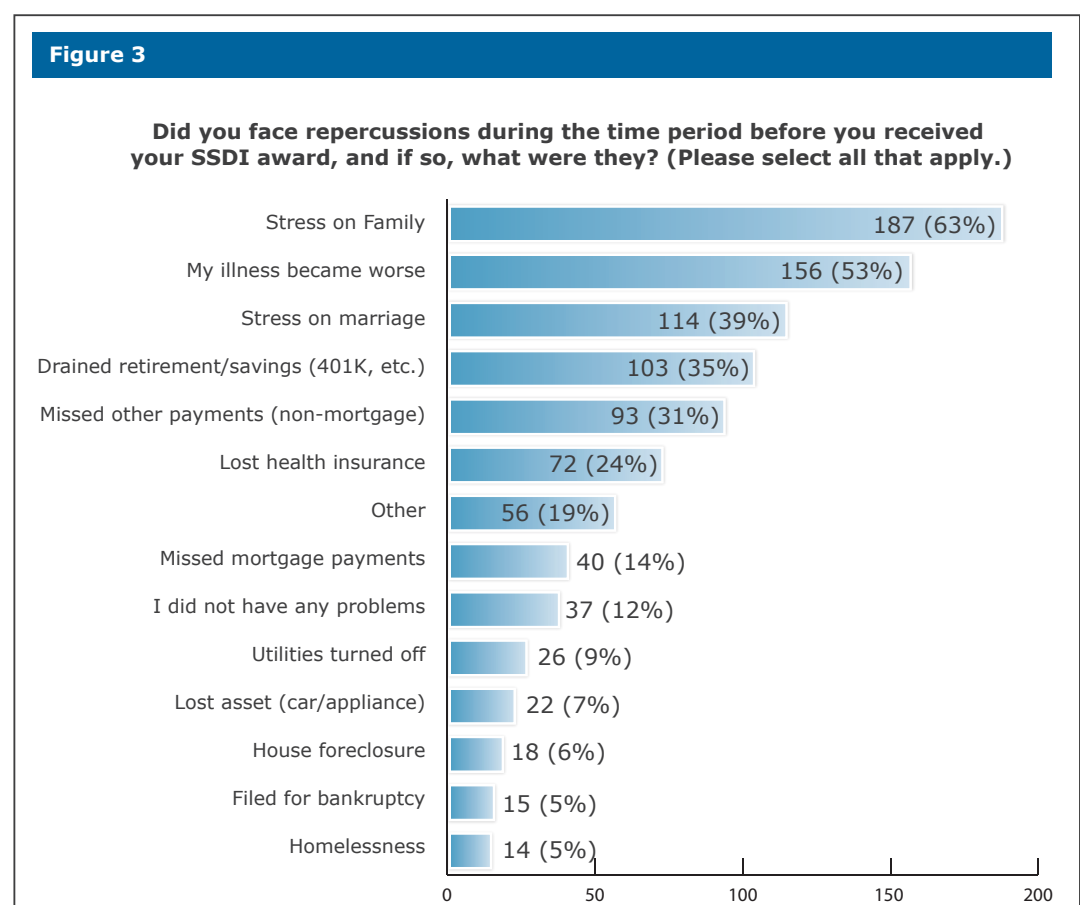
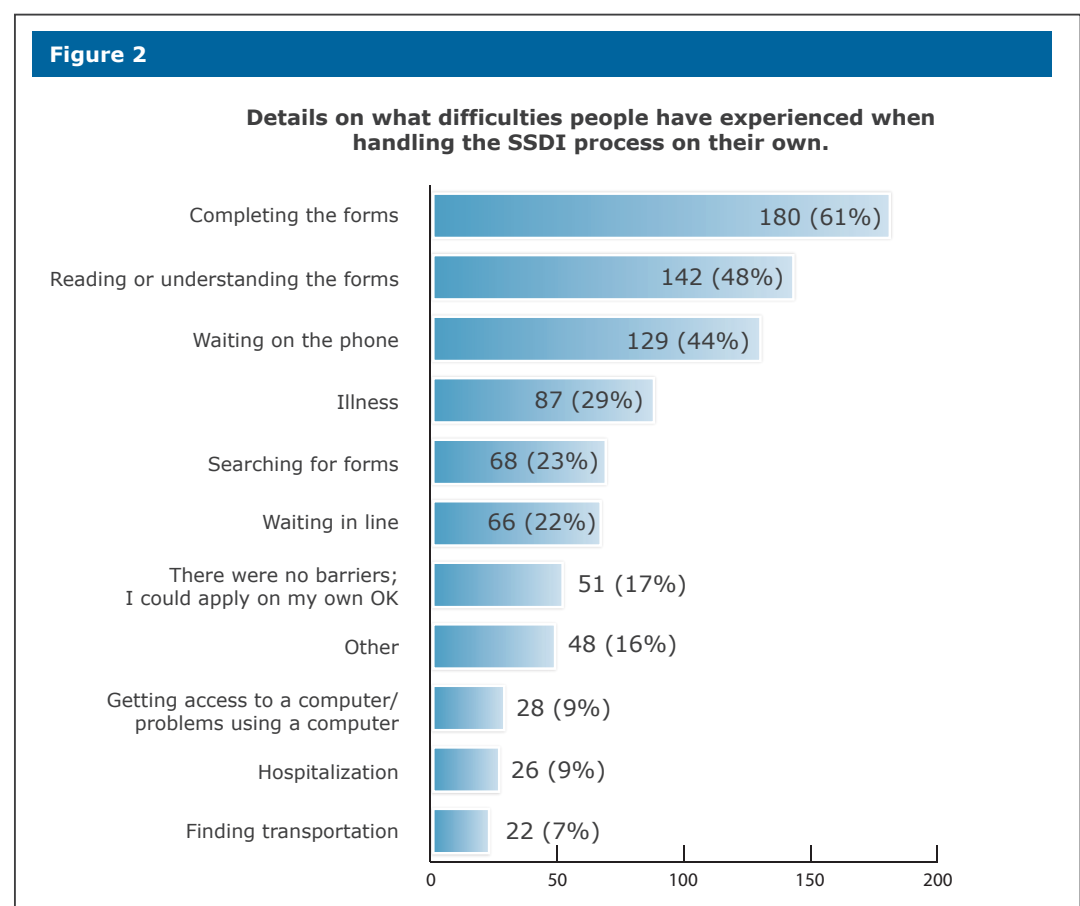


Figure 4



"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."

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)

MS patients and SSDI-

- Stress can trigger or worsen MS attacks. Letting an experienced SSDI representative handle a claim can alleviate patient stress.
- Financial worries can increase stress. The sooner patients get their SSDI benefits, the less likely they are to drain savings, miss mortgage payments or rack up credit card debt.
- 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 24 months after they are eligible SSDI.
- 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 MS 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.⁹ 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.

⁹ *The 2011 Consumer Financial Literacy Survey Final Report*, The National Foundation for Credit Counseling, http://www.nfcc.org/newsroom/FinancialLiteracy/files2011/NFCC_2011FinancialLiteracySurvey_FINALREPORT_033011.pdf

MS symptoms most commonly cited as barriers to work include fatigue, mobility and cognitive impairments.



Most Americans don't have enough savings to last 31.2 months—the duration of the average long-term disability claim.¹⁰ 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. An Allsup survey of SSDI applicants found that most people had less than \$50,000 in retirement assets, only 12 percent had a pension and 19 percent had a 401(k).

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.

MS Patients and financial considerations

- Despite their disability, most people with MS have a normal life span—MS imposes considerable costs on individuals, families, the health care system, and society.¹¹
- A 1998 survey estimated the total lifetime cost per MS patient to be \$2.2 million.¹² Major components of cost were earnings loss and informal care.

¹⁰ Council for Disability Awareness, http://www.disabilitycanhappen.org/chances_disability/

¹¹ Prescott, J., Factor, S., Pill, M., and Levi, G. (2007). Descriptive Analysis of the Direct Medical Costs of Multiple Sclerosis in 2004 Using Administrative Claims in a Large Nationwide Database. *J Manag Care Pharm.* Jan-Feb;13(1):44-52.

¹² Whetten-Goldstein K, Sloan FA, Goldstein LB, Kulas ED. (1998). *A Comprehensive Assessment of the Cost of Multiple Sclerosis in the United States*, Center for Health Policy Research and Education, Duke University, Durham, North Carolina 27708, USA.

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

The costs of healthcare and medical insurance are high and are guaranteed to get higher in years to come. According to a 2009 U.S. Census Bureau report, about 15 percent of Americans (46 million people) did without health insurance coverage at some time during 2008.

A survey of SSDI applicants showed that 24 percent lost health insurance while awaiting their award (Fig. 3).

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 patients to 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 you are in the best available plan for your 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 understand their full range of options and identify the resources available to them before and when a crisis changes their lives. Many workers have relied on their human resources department while working, turning to this support with important health and financial decisions, which generally have been restricted to the employers' emphasis and provision. Many people don't realize the multitude of options available.

With a lifelong chronic and progressive disease such as MS, the crisis often is compounded by lost employment, lost income and lost human resources support. This can leave the MS patient floundering, disoriented and frustrated. By increasing Disability Literacy:

- MS patients can plan for disability earlier in their working career, by purchasing long-term disability insurance, thinking about their healthcare options (such as COBRA coverage), and saving.
- MS 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.
- MS patients will be empowered to have discussions with their physicians about their ability to work and enlist them as advocates.
- MS patients can be proactive in determining their next steps if they must stop working.
- MS patients can access help quickly by knowing their options and taking advantage of available resources.

Disability Literacy Support

Allsup offers free comprehensive, educational and customizable assistance for employers, nonprofit organizations and their members, healthcare professionals and their patients.

- **SSDI Eligibility Screening.** Trained disability evaluation specialists explain the SSDI process and help individuals determine their eligibility. They answer a wide range of questions for those who are and those who are not eligible for SSDI benefits. If needed, Allsup specialists facilitate inquiries to the SSA to determine an individual's work history and estimated monthly benefit.
- **Community-Based Representatives.** This team educates front-line case managers, social workers and healthcare professionals about the complexities associated with SSDI benefits and eligibility. Allsup works with hospitals to substantially reduce the gap between a patient's uninsured/insured status, marginally insured status, and date of Medicare entitlement. There is no cost to healthcare providers since Allsup works directly with referred patients.
- **Allsup Place®.** This free, online community and resources portal provides comprehensive and reader-friendly information on SSDI, including medical guidelines, representation options and what to

expect at each level of the application process. Customers and visitors alike can find customized information and resources for them, no matter their disability or situation. Services include an extensive, free online Resource Center. Allsup customers also can access information specific

to their purchased services, including SSDI representation, the *Disability Life Planning Service*® and *Allsup Medicare Advisor*®. They can provide updates, interact with Allsup experts and more.

- **Speakers Bureau.** Allsup provides a range of presentations, webinars and training programs and resources to thousands of organizations nationwide. Allsup experts also are available to host live online chats, Q&A programs, webinars and other presentations for consumer and professional audiences.
- **Training.** As a complement to the speakers' bureau, Allsup experts conduct a variety of training programs. Training can be specially designed for nonprofit organization staff and volunteer,

for help lines, program managers, support group and education coordinators, information and referral specialists. In-service and continuing education units (CEUs) are available for medical professionals to meet their training requirements and enable them to answer general SSDI queries and refer to appropriate resources.

- **Materials Library.** Allsup makes available a large library of materials on SSDI, Medicare and related topics, including digital and print: fliers, brochures, posters, checklists, referral packets, answers to frequently asked questions and SSA guidelines for specific disabilities. Allsup provides resources to educate patients and family members on SSDI benefits, Medicare and financial and disability life planning.
- **Financial Information.** Free materials on financial topics, including managing credit and debt, budgeting, mortgages and foreclosures, unclaimed property, and numerous financial planning calculators are provided on the Personal Finance section of Allsup.com.
- **Healthcare Resources.** Free information on healthcare, including managing costs, drug company assistance programs and other resources are provided in the Disability and Managing Healthcare Costs section of Allsup.com.
- **Websites.** Allsup's full library of online information can be found at Allsup.com, All Things Disability blog, AllsupCares.com for healthcare professionals, AllsupAlliances.com for nonprofit partners, among others.
- **Community.** Allsup supports a wide array of organizations that help people with disabilities at both the national and local levels. Allsup team members foster the spirit of True Help[®], volunteering and donating to organizations such as United Way, Centers for Independent Living (CILs), crisis centers, reading services for those with visual impairments, hospice groups, mental health organizations, HIV/AIDS outreach, and other organizations in metro St. Louis area and nationwide in the communities where employees live.

“In retrospect this was one of the scariest times of my life. Would we be able to keep our home? I did not know.”—Individual with MS, on going through the SSDI application process.

“It was like a whole weight had been lifted off me. It was great knowing someone was there helping me through this, and now I just needed to focus on taking care of myself.” —Individual with MS who had been denied SSDI benefits 12 times before Allsup helped her obtain the benefits she paid for during her three decades of work.



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