

PROLONGING WORK SUPPORTS TO KEEP YOU ON THE JOB

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Today's Moderator



Katie Metz

Manager, Financial
Empowerment &
Inclusion

National Disability
Institute

Today's Agenda

- Welcome
- Financial Wellness and Individuals with MS
- Overview of What Having a Job Means to Financial Wellness, the Extension of Support Networks and the Importance of Providing Structure in Life Activities
- Considerations directed to Knowing Yourself Well and Your Capacity to Work, Disclosure of Disability, Returning to or Remaining on the Job as a person who has MS
- Questions & Answers
- Resources
- Suggested Next Steps & Wrap Up

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National Disability Institute

A national research and development organization with the mission to promote income preservation and asset development for persons with disabilities and to build a better economic future for Americans with disabilities.



What is Financial Wellness?

- We define financial wellness as the state of a person's finances with the intent of working towards financial behaviors that limit stress and the impact of stress on one's daily life.

Financial Wellness



National Poverty Estimates

Individuals ages 18-64

- For individuals without disabilities, 12.4% had income below the poverty level over the past 12 months
- For individuals with disabilities, more than 2x that rate – **27.8%** had income below the poverty level.

Source: U.S. Census Bureau, 2011 American Community Survey

- No group in America is more in need and more deserving of economic recovery

- For millions of working age adults with disabilities a dependence on public benefits for income, health care, food, and housing becomes a trap that requires staying poor to stay eligible

The Americans With Disabilities Act

- *The Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals;*
42 U.S.C. § 1201(a)(8) (2005)
- *the continuing existence of unfair and unnecessary discrimination and prejudice denies people with disabilities the opportunity to compete on an equal basis and to pursue those opportunities for which our free society is justifiably famous, and costs the United States billions of dollars in unnecessary expenses resulting from dependency and non-productivity.*
42 U.S.C. § 1201(a)(9) (2005)

Why is Financial Wellness Important?

- Impacts mental and physical health.
- Positively impacts self-concept.
- Changes status with other community stakeholders.
- Directly impacts quality of life.

Financial Wellness and MS

- A recent survey conducted by MSAA and NDI involving individuals with MS indicated:
 - 55.1% of households earn less than \$35k annually, 16.4% earn less than \$50k but more than \$35k annually.
 - When asked about the ability to pay all of their bills in a typical month, 32% have a “very difficult” time paying their bills in a typical month, 46.9% reported a “somewhat difficult time”.
 - 43% of respondents reported that their financial status has affected their ability to access medical care at some point.

Financial Wellness and MS

- A recent survey conducted by MSAA and NDI involving individuals with MS indicated:
 - 71.7% of respondents do not have enough savings to cover 3 months expenses.
 - 67.1% of respondents reported that their finances were worse since their MS diagnosis.
 - 73.7% of Respondents reported that they were not aware of/have not used financial stability programs (EITC, IDA, FSS, PASS – you will learn about these in subsequent webinars)

Financial Wellness Strategies Exist

Financial Literacy

Budgeting

Credit Repair

Getting Banked

Use of work incentives

Use of tax incentives

Volunteer Income Tax Assistance

Earned Income Tax Credit

State Medicaid

Buy-In

Programs

Family Self-Sufficiency Programs

Individual Development Accounts

Assistive Technology Loan Funds

Student Loans

Retirement Accounts

Post-secondary Education

Employment

Self-employment

Micro-Enterprise

Home Ownership

Protection and Advocacy, Taxpayer Advocates, Credit Counseling
Volunteer Income Tax Assistance, Work Incentive Planning & Assistance



Today's Presenter

Karen McCulloh, RN, BS
National Disability Institute



Karen McCulloh

Karen McCulloh is a graduate of Grant Hospital School of Nursing in Columbus, Ohio and Loyola University of Chicago. She is currently licensed to practice nursing as an RN in the state of Illinois. Karen worked in both the clinical and community health arenas for many years and in 1990 established her own for-profit private practice focused on Community Health Disability Education. As an entrepreneur, she owned her own business for 15 years. Karen is also co-founder of the National Organization of Nurses with Disabilities.

In 2005 Karen accepted a founding Executive Director position for a new initiative disabilityWorks located at the Chicagoland Chamber of Commerce that was the result of Mayor Daley's Task Force on the Employment of People with Disabilities. The goal of the initiative is to remove barriers that keep people with disabilities from becoming employed with a focus on both the supply and demand sides to employment. She was instrumental in moving this initiative state wide in 2007 while working with the IL Dept. of Commerce & Economic Opportunity.

Karen McCulloh, continued

During the time Karen was executive director she held a Federal Appointment to serve on the Job Corps National Advisory Committee and served on President-elect Obama and Biden's Transition Team in 2008.

Karen resigned as the Executive Director of disabilityworks in 2010 to re-establish her own business. She received a Presidential Appointment from President Obama in 2011 to serve on the AbilityOne Commission. In 2012 she accepted the founding National Disability Institute Project Director position for a new TA Center funded by DOL ODEP – the LEAD Center. She served one year and has transitioned out of this position into the Director of Special Projects before she retires at the end of 2013.

Positive Aspects to Having a Job

- Provides infrastructure in our Lives—Gives a Reason to Get Up and Show Up for Work
- Reduces Isolation
- Improves a Sense of Self Worth—People rely on Us for the Skills We Have
- Offers a sense of Achievement
- Respected by Colleagues, Friends & Family
- Enhances Our Sense of Purpose in Life
- May be Able to Financially Help Others
- Offers Opportunities to Extend Social and Professional Relationships with Colleagues at Work

Questions/Concerns about Returning to or Staying On the Job

- National Disability Institute's Acorda series of webinars has already addressed public benefits in a previous webinar. The question about public benefits continues as an ongoing concern for people who are thinking about returning to work or are newly diagnosed and recipients of benefits.
- If you return to work and are concerned about jeopardizing your public benefits such as SSDI, SSI or private long term disability insurance (LTD) benefits, You can return to work and keep your SSDI benefits while receiving a monthly salary of up to \$1,040. If you are blind the income is up to \$1,740.

Questions/Concerns Continued

- If you receive a combination of SSDI and private long term disability (LTD) insurance income—you must check the policies of returning to work as you could jeopardize LTD.
- If you are a recipient of SSI the calculations for income is much different.
- Do the Research--Ask Questions--Speak with a Benefits Planner--Review your long term disability insurance plan in order to make informed choices.

Know Yourself Well!

Identify Challenges and Create Solutions That May Acknowledge the Need for Work Supports

- Individuals who have MS may have some similar challenges associated with their disability but many do not
- Every person with MS is different and each individual must evaluate their own situation

Know Yourself Well continued...

Identify Challenges and Create Solutions That May Acknowledge the Need for Work Supports

- Some individuals become employed knowing that they have MS but did not choose to disclose their disability because at the time they did not believe they required any work supports /accommodations
- MS may be non-apparent to others.

Know Yourself Well continued....

- Disclosing MS or any disability is a choice that is protected under the Americans with Disabilities Act
- Disability status may change which may require revisiting disclosure and request for work supports.
- If you do not disclose your disability you are not legally eligible to receive accommodations.

Think through Your Challenges That Impact Your Work Capacity

Becoming aware of your challenges will assist you in developing strategies to problem solve for yourself or to seek assistance to help resolve

Cognitive Dysfunction Spectrum Challenges

Common challenges that may be associated with MS.

- Cognitive deficits may go unnoticed and does not necessarily impact intelligence.
- Cognitive deficits experienced by people with MS are frequently not discussed with their physician.
- It is estimated that approximately 60 percent of people with MS experience some degree of cognitive deficits that may be associated with the cognitive/thinking process. Some people with MS have no difficulty in processing information what-so-ever.

Categories of Cognitive Dysfunction

- **Attention:**
 - Concentration—Short attention span impacts the ability to stay focused on a task.
 - Multitasking requires attention to be divided where thought processes must move quickly from one task to the other and may be difficult for some people with MS to accomplish.

Categories of Cognitive Dysfunction Continued

- **Memory:**
 - Long term memory does not seem to be impacted
 - Difficulty remembering where short term memory is impacted, keeping appointments, processing sequential information and recalling conversations.
- **Executive Function:**
 - Difficulty may be evident in the ability to plan, organize schedules, your office, be involved in problem solving and decision making.

Other Issues Associated with Cognitive Dysfunction

- Thinking process may be slower.
- If you become too tired you cannot process information as well.
- Co-existing disabilities such as depression or dealing with chronic pain may mask or worsen cognitive deficits.
- Cognitive deficits may improve if associated with the inflammatory results of a relapse once remission occurs.
- Some medications can increase cognitive deficits.
- Increased stress and anxiety can negatively impact cognitive processing abilities—this is true for anyone.

Implementing Strategies That May Substitute for Memory

- Reduce distractions by working in a quieter environment.
- Work with a smaller number of people in order to follow conversations with greater ease.
- Keep socially and intellectually active.
- Give yourself more time to accomplish a task.
- Follow up quickly at home or work by recording items you want to remember in a way that you know you will review.
- Use a smartphone, computer calendar or iPad to keep calendar updated.
- Use a spiral notebook to record a hard copy of information while out of home or office so that items may be saved in sequential order—list date, time and location at top of page.

Implementing Strategies That May Substitute for Memory Continued

- Leave a message on your own voice mail message system to remind yourself of task or appointment you need to keep.
- Request people to e-mail you when there is a limitation in listening to details while at the same time there is an inability to simultaneously take notes.
- Request a person to call you back and leave a message on voice mail in order to assist your comprehension and to process information to be reminded of schedule commitments and other activities
- Review your calendar frequently.
- Review calendar for work over the weekend to keep pace with the next week commitments.

Other Challenges That May be Present

What is your physical strength ability?

- Are you exercising regularly? If not, speak with your physician and set up an exercise routine by working with a physical therapist that set up exercises that will enhance physical capabilities and improve your endurance.
- Research demonstrates that exercise enhances your energy level and can improve your balance and walking.

Other Challenges Continued

What is your Fatigue Level?

- Many people with MS share that they have a fatigue factor they must learn to live with in managing their time while continuing to be effective on the job or at home in taking care of responsibilities.
- 85 percent of college students with MS who responded to an online survey identified fatigue as their greatest educational challenge followed by cognitive concerns.

Many factors impact the onset of fatigue and reduce stamina including living or working in environments that are too hot with high humidity or too cold

- Ensure your work and home environments offer you the opportunity to control the temperature that will work best for you to maximize your abilities.

What Mobility Limitations Do you Have?

- Walking up and down stairs
- Standing for long periods of time
- Walking long distances
- Need to Use a cane
- Need to Use a wheelchair or scooter
- Is your work and home environment accessible?
- If you are thinking about returning to work what accessible transportation options to you have in the area in which you live?
- What type of work environment do you need?
- If your disability status has changed what strategies do you need to implement to address mobility constraints?

Vision Challenges

- Some people with MS experience vision loss due to scotomas (blind spots) forming in their visual fields—requires physician intervention.
- Optic Neuritis, inflammation of the optic nerve can cause visual deficits and blindness—requires physician intervention.
- Double vision occurs when the brain is not able to convert images from both eyes into one.
 - Can last a few weeks or a few months.
 - Frequently associated with a relapse or “flare up” of MS.

Vision Challenges Continued

Strategies and Treatment for Double Vision:

- Eye patch used to block image in one eye as prescribed by doctor
- Prism lenses fit into eyeglasses will redirect the way light enters the eye as prescribed and adjusted by an ophthalmologist
- Reduce eye fatigue by reducing computer use and reading
- Use audio books
- Increase font size of print on computer to reduce eye strain
- Improve lighting and decrease glare
- Medications as prescribed by your physician
- Learn about assistive technology software that can be downloaded on to your computer that can provide large print and screen reading functions

Communication Challenges

- Some people who have MS will have slurred speech or slow speech or lose their speech ability altogether.
- Some people with speech impairments that impact their communication ability will use a voice synthesizer (what is often called an Augmentative and Alternative Communication device). They will push keys that may look similar to a small computer keyboard and the voice synthesizer speaks the words they want to communicate to others.

Disclosing Your Disability

- The decision to disclose to an employer that you have MS is up to you
- Disclosing can be a challenging experience so be knowledgeable of your disability. You do not have to sell your disability; you emphasize your skills
- Disclosing that you have MS does allow you protections under the ADA
- People with MS are not obligated to disclose their disability unless having MS is likely to affect their job performance
- If work supports/accommodations are needed to meet the essential functions of a job you are applying for you must disclose your disability in order to be successful
- Accommodations are not meant to make up for lack of skills, knowledge or abilities

Disclosing Your Disability Continued

- Some people fear that if they disclose they have MS they will be viewed by an employer with negative preconceptions they may have about disability
- Disclosure of a disability is confidential and only personnel that are most involved should be aware that you have a disability.
- Disclosing that you have MS opens up the opportunity to honestly discuss work supports/accommodations that you need.
- Prepare a list of written accommodation requests and make suggestions on products, adaptive devices or assistive technologies that you may need. This is where your own research begins to play an important role. Set yourself up to succeed!
- An employer is not bound to purchase the exact product you suggest if a different product performs the same function and costs less.

Enhance Your Employment Goals

You can enhance your employment goals by combining your disability knowledge of self to build capacity to return to or stay at work by identifying the work supports you need.

Questions to Ask Yourself:

- Are you able to Define your Work and Health Situation
- Should I work full or part time
- Re-Identify skills and Contributions You Can Make
- What is Your Passion
- Ask Yourself What is Important to Me
- What Solutions Have you Identified to Address Challenges—You are the Driver--
Remove Barriers
- Are you your own best Self Advocate and Able to Ask for What You Need
- What is Your Career Dream

Enhance Employment Goals Continued

21st Century Opportunities:

- In the 21st Century more opportunities are open for people with all types of disabilities to find a job or remain employed
- Technology has opened the doors to career opportunities for people with disabilities that were not open in the past
- More people with disabilities are enrolled in and returning to colleges and universities that assist them in following an educational career path to pursue their employment dreams
- You are never too old

What are Your Options?

- If not Work—Volunteer—Volunteer Work Helps to Build and Renew Skills
- Consider Taking an Online Course in an Area of Employment Interest
- Create a Facebook.com page to familiarize yourself to Virtual Social Networking
- Explore Facebook pages for Information on Employers and Click on “Like” for Organizations that You are Interested
- Join LinkedIn.com, explore members and make connections with former colleagues (and their friends) to extend your professional networks
- Join online groups of interest and Enter Into Discussions
- Consider working from home by telecommuting
- Consider starting your own business and being self employed
- Investigate Social Security Return to Work-- Work Incentives

Questions & Answers

Work & Health Resources

- **Accommodations**

- ADA National Network - <http://adata.org/Static/Home.aspx>
- JAN – Job Accommodation Network - <http://askjan.org/>
- Independent Living Resource Centers - <http://www.ncil.org/directory.html>

- **Maintaining and Obtaining Employment**

- State Vocational Rehabilitation Agency - <http://rsa.ed.gov/people.cfm>

- **Obtaining Employment**

- Department of Labor – One Stop Centers - <http://www.servicelocator.org/>
- Federal Hiring of People with Disabilities - http://www.dol.gov/odep/pubs/scheduleA/abc_Job_Applicants_ODEP_508%20compliant.pdf

Work & Health Resources Continued....

- **Collaborative Decision Making**
 - Informed Medical Decisions Foundation
<http://informedmedicaldecisions.org/>
- **Disability Insurance**
 - **Guide to Disability Income Insurance** is a publication to help consumers understand and evaluate their need for disability income protection <http://www.ahip.org/Issues/Documents/2009/Guide-to-Disability-Income-Insurance.aspx>
- **An Employer's Guide to Disability Income Insurance** helps employers understand the benefits of offering disability income coverage to their employees, and introduces key concepts regarding the provisions of group disability insurance policies <http://ahip.org/Issues/Documents/2007/An-Employer%e2%80%99s-Guide-to-Disability-Income-Insurance.aspx>
- **National Organization of Nurses with Disabilities**
 - <http://www.nond.org/>

Suggested Next Steps

1. Consider the Following Questions:

- What is your view of yourself as a person with MS?
A positive attitude and self-perception makes all the difference in what you believe and can accomplish.
- What is it that you want to do?
Make up your own mind and move forward taking it one step at a time.
- What additional or potential work supports do you need to remain at work or return to work?
- What is your comfort level in asking for what you need?
Are you your own best self advocate in setting up a conversation with your employer to request assistance, supports or accommodations you need while working?
- How prepared are you in knowing about work supports that are available?
Have you done the research?

Suggested Next Steps

2. Think about how you can create solutions directed to any physical, cognitive or emotional challenges that you may view as barriers to returning to or remaining on the job.
3. After you have identified the challenges, obtain more information on how you can learn to do “old things new ways.”
4. Set goals (plan of action) and follow-through. Identify first step, accomplish and go to the next step. Set a timeline.
5. Identify skills you may need to improve or develop.
6. Share with us your experience.

We will send out emails over the next few months to offer you a chance to share your experience.

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