



2015 ECD Global Alliance Patient/Family Gathering

Financial Stability

Susan C. Robertson, PhD, OTR/L, FAOTA



National Institutes of Health
Clinical Center

Overview

- ▶ Assessing functional changes
- ▶ Sick/family leave
- ▶ Employer's short and long-term disability
- ▶ Social Security Disability Insurance (SSDI)

Assessing Functional Changes

- ▶ Early warning signs
- ▶ Symptom severity and management
- ▶ Effect on mobility, endurance, thinking, social interactions, emotion regulation
- ▶ Effect of symptoms on performance, pacing, persistence, and job maintenance

How are you protected?

- ▶ Americans with Disabilities Act (Title One)
- ▶ Protection from job-related discrimination
- ▶ Essential functions of the job

ADA 800-669-3362

www.ada.gov

Accommodations

- ▶ Phased-in work place accommodation
- ▶ Performance-based

Job Accommodation Network (JAN)

www.askjan.org

800-526-7234

TTY 877-781-9403

Sample Accommodations

- ▶ Temperature sensitivity
 - Fan/heater at work station
 - Flexible scheduling during extreme weather
- ▶ Fatigue
 - Ergonomic work station
 - Mobility aid
- ▶ Migraine
 - Task lighting and glare guards
 - Reduce environmental noise

Symptoms Persist

- ▶ Accommodations no longer adequate
- ▶ Cannot perform essential functions with accommodations
- ▶ What's next?

To Work or Not?

- ▶ Decision criteria
- ▶ Acceptance
- ▶ Self-honesty
- ▶ Judgment
- ▶ Quality of life

Sick/Family Leave

- ▶ Sick leave
 - Accumulated
 - Donated sick leave
- ▶ Family medical leave
 - Exhausted annual leave
 - Up to 12 weeks of unpaid leave
 - Maintain health insurance
 - Return to work -- Same position or equivalent

Employer's Disability

- ▶ Short-term
 - Temporarily disabled (3 to 6 months)
 - Able to return to work
- ▶ Long-term
 - Unable to work
 - Total or partial disability?
 - Apply for Social Security Disability
- ▶ Employer's insurance varies. *Know what's covered well before you need to use it!*

Social Security Disability

- ▶ Federal insurance program
- ▶ For workers who have paid into the Social Security Administration (SSA) through payroll deductions
- ▶ Not a needs-based program

ssa.gov socialsecurity.gov

800-772-1213

Eligible?

- ▶ Worked 5 of last 10 years
- ▶ Have been or will be unable to work for a year
- ▶ Contributed to SSA 16 quarters
- ▶ Medically approved disability severe enough to keep you from working

http://ssa.gov/disability/disability_starter_kits.htm

Severity of Impairment

- ▶ Restrictions in daily living
- ▶ Restrictions in social functioning
- ▶ Concentration, pacing, and persistence
- ▶ Periods of decompensation

Definition of Work

- ▶ Substantial gainful activity (SGA) is Social Security's definition of work
- ▶ In 2015, SGA is \$1090/month
- ▶ Earning less than \$780/month may be defined as “not working”
- ▶ SGA is adjusted annually

<http://www.socialsecurity.gov/OACT/COLA/sga.html>

Begin Application

- ▶ 3 parts
 - Application
 - Adult Disability Report
 - Medical Authorization Release Form
- ▶ Complete forms online
 - Ssa.gov / Disability / Begin application
- ▶ Request compassionate review for ECD
 - Include this in REMARKS section of application
 - 1-800-772-1213 (national toll-free number)

Disability Determination Services

- ▶ Disability Determination Services (DDS) makes a determination of disability
- ▶ Medical review
 - Medical reports from past and current providers
- ▶ Additional information about you
 - Function Report
 - Work History Report

Timeline

- ▶ From initial screening to notification of decision
 - SSA to DDS = approx 1 month
 - DDS decision process = approx 3 months
 - SSA notification = approx 1 month

5–6 months

Notification of Decision

- ▶ Awarded
 - Post eligibility processing
- ▶ Denied
 - Appeal
 - Request for Reconsideration: File within 30 days
 - Administrative Law Judge: hearing in 1 year

Biggest challenges

- ▶ Accepting health condition
- ▶ Describing embarrassing functional losses
- ▶ Describing function in ways that illustrate severity of impairment
- ▶ Being very specific

Keep at it

- ▶ Complex process
- ▶ Confidential
- ▶ Detailed
- ▶ Ask for the help you need
- ▶ The national 800 number keeps a record of your progress

Self Care

- ▶ Taking good care of yourself can take many forms
- ▶ Managing financial stability can have an impact on stress and symptoms
- ▶ Completing the application can be an emotional drain
- ▶ The goal of healthy self care is worth the effort – ask for help

Assistance

- ▶ Local Social Security office
- ▶ Lawyers and legal firms
- ▶ Social workers
- ▶ Case Managers

srobertson@cc.nih.gov

