



IMPROVING OPPORTUNITIES FOR ALL!

3rd International Rare Neuroimmunologic Disorders Symposium
Friday, July 18, 2008

**Self Advocacy
and
Employment with Disabilities**

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Self Advocacy and Employment with Disabilities

Advocacy is a set of hands-on technical skills and practices needed to effectively press for change.

Advocacy is the foundation of active citizenship, a process through which ordinary people learn to participate in decision making at all levels.

Advocacy is identifying priorities, crafting a strategy, stepping forward, taking action, and achieving results which are critical steps to finding one's voice, making oneself heard, and shaping one's future.

Successful Advocacy is when people are empowered with the dignity and confidence to act and a world of possibilities opens up.

Institute for Sustainable Communities, Advocacy and Leadership Center
http://www.iscvt.org/what_we_do/advocacy_and_leadership_center/



Self Advocacy and Employment with Disabilities

Unleashing the advocate in each of us...

SELF ADVOCACY AND EMPLOYMENT

- **Advocates must look at the whole picture and ask critical questions:**



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Self Assessment:

- **Health**
 - Current condition, limits and abilities
- **(Common issues: Fatigue, mobility, coordination and balance, weakness, depression, cognitive symptoms and others)**
 - Everyday Expenses
 - Needs
- **Basic Needs**
 - Housing
 - Food
 - Clothing
 - Household Expenses
- **Education/Training**
- **Work Experience**
- **Work goals**
- **Availability**
 - Of Work
 - To Work
- **Transportation**
- **Current Supports & Costs**
- **Needed Supports & Costs**
- **Current Benefits**
 - SSI
 - SSDI
 - Medicaid
 - Medicare
 - Insurance
 - Other
- **Current Income & Resources**



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Health Advocacy

- **Health advocacy is critical. If you are not healthy and cannot stay healthy, you cannot work or stay gainfully employed.**
- **Self—let your needs be known**
 - Inform doctors & providers
 - Communicate with insurance
 - Ask questions
 - Learn as much as you can
 - **YOU ARE HERE—Great Start!!!**
- **Self & TM**
 - Educate your healthcare providers
 - Share TMA Journal
 - Give to your physicians
 - Give to your area ER departments
 - Communicate your Experiences
 - Promote Research
 - Grass roots efforts-email representatives
 - Support Groups
 - Fund Raising for Project Restore and TMA



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Education & Training

- **Primary Education**
- **Post Secondary Education**
- **Vocational Training**
 - **State VR Departments (Not a one shot deal)**
 - **Transition**
 - **Pre-Employment**
 - **Employment**
 - **Post-Employment**
 - **Re-Employment**
 - **School Voc training**
 - **Employment Networks**
- **Specialized Training**
- **Continuing Education & Certifications**



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Transition to Work

- **School to Work**
- **Post illness to Work**
 - **To previous job**
 - **To new job**



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Work--- Things to think about...

- **Social Security**
 - **SSI**
 - **Income/Resources \$2000/\$3000 couple**
 - **2008 Benefit \$637 /\$956 couple**
 - **Following is a list of states that supplement the basic SSI amount with a link to more information about that state: California Hawaii Massachusetts Nevada New Jersey New York Pennsylvania Rhode Island Vermont Washington D.C.**
 - **Earnings=\$85 exempt then \$2 earned less \$1 benefits**
 - **Students with disabilities— Do not count up to \$1,550 of your earnings a month in 2008 (maximum of \$6,240 for 2008) when they compute your SSI payment amount if you are under age 22 and go to school or are in a training program on a regular basis.)**
 - **SSDI**
 - **SGA \$940/Blind SGA\$1570**
 - **9 Trial Work Months (\$670)**
 - **IRWE**
 - **Subsidy**
 - **PASS**
 - **Ticket**
 - **EXR-Expedited Reinstatement**



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Insurance

- Medicaid**
- Medicare**
- Private**
 - Pre-existing Conditions**
 - COBRA**



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Paid

- Maintaining previous or current employment**
- Part time**
- Full time**
- Stipends**



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Unpaid

- Barter system**
- Volunteer**



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Disclosure

Reasonable Accommodations

- Modifications**
- Assistive Technology**



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RESOURCES

- **Transverse Myelitis Association**
<http://www.myelitis.org/index.html>
- **TM Center at Johns Hopkins**
<http://www.hopkinsneuro.org/tm/>
- **Jim Lubin's disABILITY Information and Resources**
<http://www.makoa.org/index.htm>
- See Handout for more helpful resources



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ADVOCACY OPPORTUNITIES

- **Current Issues that may affect you:**
- **ADA Restoration Act**
- **Medicare In-Home Restrictions**
- **Medicare Therapy Caps**
- **Stem Cell Research**
- **The Elections—VOTE**

- **Ways to become involved:**
- **Project Restore <http://www.hopkinsneuro.org/restore/>**
- **Transverse Myelitis Association <http://www.myelitis.org/index.html>**
- **Contact your Representatives and find out about current bills and laws:**
- **Library of Congress THOMAS <http://www.thomas.gov/>**
- **House of Representatives <http://www.house.gov/>**
- **Senate <http://www.senate.gov/>**
- **See Handout for more Advocacy information**

Thank you all for this opportunity
and thank you to



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