Do you want a job, a career and greater independence? As an individual with spinal cord injury (SCI), your answer may be a booming “yes!” After all, working is what people do, and there is no reason that you should not be working too. Individuals with SCI are living longer, healthier lives than ever before. The national unemployment rate is at its lowest rate in over 30 years. The Americans with Disabilities Act (ADA) has made it illegal for employers to let disability overshadow ability when it comes to competing for a job. Then everyone who answers, “yes,” is probably working. Right?

Wrong! Many individuals with SCI, who could and would work, do not have jobs. The National Spinal Cord Injury Statistical Center (NSCISC) reports that only about 35% of individuals with paraplegia and about 24% of individuals with tetraplegia have jobs 10 years after injury. This means that about 2 out of 3 people with paraplegia and at least 3 out of 4 people with tetraplegia are unemployed 10 years after injury. This amounts to a total of about 70% of individuals with SCI.

Although there are some people who choose not to work, many studies have been done to find out what determines the likelihood of getting a job for those of you who want to work. For example, one factor that improves your chances of working after injury is whether or not you had a job at the time of injury. It is true that work experience is important when you are competing for a job. However, NSCISC also reports that almost 64% of individuals were working at the time of injury. This 64% employment rate before injury is almost opposite of the 70% unemployment rate ten years after injury.

The fact is that most individuals with SCI are not working. If you want to work, you need to know what you can do to get a job.

The good news is there is something that you can do. Education is the single most important factor in the employment of individuals with SCI. If you have an education, you are not guaranteed to get a job, but your chances of working will dramatically improve with education. This is true no matter who you are or what your level of injury. With an education you gain knowledge in many areas. This fact gives a person with a college degree more job opportunities than a person with no degree.

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Table 1 shows the relationship between work and education. The table shows that about 17% of individuals with spinal cord injury between levels C5 and C8 who have a high school diploma are working; about 33% of individuals with the same levels of injury who have an Associates degree are working; about 52% with a Bachelors degree are working; and about 62% of individuals with SCI between levels C5 and C8 who have a Masters or Doctorate degree are working.

What To Do

Each state has federal funding to offer vocational rehabilitation services (VRS), supported employment, and independent living services. The qualifications for VRS are different for each state, but the purpose of these services is to help you get to work and be as independent as possible. States know that every $1 spent helping you get to work brings $20.02 back to the state’s economy through your employment.2

If you have a job at the time of injury, your goal may be to return to the same job or re-train for a similar job with the same employer. VRS can help you. If you do not have a job at the time of injury or you cannot return to your old job, getting an education can be the key to getting another job.

Many individuals with SCI do not have the money to pay for school. VRS can also help you pay for the education you need to prepare for work. The phone number of your state’s VRS provider is on page 7, and they may want you to apply for other financial assistance. You want to look for money that you do not have to pay back, like a scholarship or Pell Grant, but you have to apply to see if you qualify.

After you get in touch with your VRS provider, it is time to look at you. This is something that everyone must do. Typically, a VRS counselor or case manager works with you to help determine your interests and needs. You may or may not know what kind of job you want or what you may like to do. Remember, it is not necessarily the job that you select as much as it is your area of study. The area of study that you select determines the types of work that you are most qualified to do. It is important to choose an area that you like because you do not want to put a lot of time and effort into getting a job that you are not going to enjoy. Some states may offer psychological and vocational tests to help you select the best area of study for you. Your counselor may suggest that you take some tests to help you recognize your interests, abilities, personality, and what kind of life style you want.

You want to look at the Occupational Outlook Handbook for help in selecting an area of work interest. This handbook has information on jobs throughout the country and assists people in making decisions about their work. It also describes what workers do on the job, working conditions, the training and education needed, earnings, and expected job prospects in a wide range of occupations. There are probably jobs in the handbook that you did not know existed. It is available on the Internet at http://stats.bls.gov/ocohome.htm or at your local public library.

The next step is to work with your vocational rehabilitation counselor to plan what education or training you need to prepare for a job. You have to decide the best way to get your education. You may need to go to a college or technical school. This can be a problem if you do not live in an area close to the type of school you want to attend. You may need transportation, or you may want to relocate to another area. Relocating can be difficult because you may have to change your daily routine or move.

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away from the support of family and friends. It may help to ease problems if you relocate to a place where it is easier to find qualified attendant care, accessible transportation, and more opportunities for employment after you complete your education.

Another suggestion is to live on a college campus. You can usually get to your classes in your chair if you live on campus. This means you do not have to worry about transportation to and from class. Your counselor can also help make the move easier by referring you to independent living support services in the area.

**Getting A Job**

After you have worked hard and finished your education, you need to know how to search for a job. "Networking" is probably the best way to find a job. Networking is getting to know other people working in your area of interest. You can get to know these people through other friends, internships, part-time work or professional organizations and associations. The idea is to hear about job openings from your "network" of people.

There are also other ways to find a job. VRS may help you find a job and provide you with any special equipment or assistive technology that you might need to do that job. Almost all colleges and technical schools have career services that help you prepare a resume, practice interviewing skills, and other job related services. Employment agencies can also help. There are job listings on the Internet and in the "Classified" section of your local newspaper. If you can relocate, you can expand your search to look for job opportunities in other areas.

You need to be realistic when looking for a job. As an individual with spinal cord injury, you have to consider your income and insurance. Not many people start at a job that pays $75,000 a year and provides insurance. Luckily, Social Security and Supplemental Security Income (SSI) now offer incentives that allow you to work for some time without losing your benefits. You can read about these incentives on page 5. If you are searching for a professional job, these incentives give you the opportunity to be flexible. You may want to look at an "entry-level" job. This type of job allows you to enter a company at a lower pay and work your way into a higher paying job. Or, you may want a specific job that requires experience that you do not have. The only way to get experience is to work, so you may want to be open to work other jobs that allow you to gain the experience needed for the job that you do want.

You should be ready to sell yourself when you are looking for a job. This means that you have to find things that set you apart from the others who are competing for the same job.

It Takes Work to Get A Job

Individuals with spinal cord injury can, and do, work in a wide variety of jobs. You have to take control if you do not work but do want a job. You can call your state vocational rehabilitation service and take advantage of all the services that are available to help you reach your goal. It is important to make an effort to learn what you need to know to qualify for as many jobs as possible. Be sure to search for an area of employment that you like but also gives you the most opportunities for finding a job.

Above all, do not give up! It Takes Work to Get A Job, and it is something only you can do. There is a job for you, but it may take time to find the job that is right for you. Once you find the right job, it may take time to work out the "kinks" of managing other daily living activities while you are working. But once you find a job, you will see that it is worth all of the work.

**Note**

*It Takes Work to Get A Job* was written by the editor with factual assistance from Pam Mobley, Unit Supervisor, Alabama Department of Rehabilitation Services.


2 - Determined through a formula calculated by the Federal Office of Management and Budget.
As an individual with spinal cord injury (SCI), your health has a direct impact on everything that you do. It can be impossible to fully participate in daily activities, like going to school or work, if you have health problems. Two such problems are pain and pressure sores. Each of these problems can, and does, severely limit one's ability to enjoy everyday activities. Therefore, it is important to know some of the things that you can do about these problems.

**Pain** is a major issue for many individuals with SCI. Those with pain can fall into a repeating cycle of pushing themselves until the pain becomes severe enough that they must rest. This cycle often results in negative consequences like periods of increased pain and fatigue, anticipating pain, increased tension, worry/anxiety, a decrease in the ability to do daily activities, and a tendency to totally avoid daily activities.

**Pacing of activities** is a method that may help to manage everyday pain and improve quality of life.

1. List all activities that you frequently overdo that result in an increase in your pain or fatigue. For example, if typing on a computer tends to increase your pain, list "typing on a computer."
2. When doing each activity on your list, make a note of the time that it takes for you to experience an increase in pain or fatigue. For example, make a note if your pain or fatigue increases after 30 minutes of typing on the computer.
3. Set a time limit for doing the activity that is well below the point when you experience an increase in pain or fatigue. When you reach that time, stop and rest. For example, stop and rest after 15 minutes of typing on the computer.
4. Return to the activity after your rest period. The time that you spend resting will vary. You want to have enough rest time for you to continue the activity as outlined in numbers 2 and 3.
5. Do not get in a rush to complete any activity. You should slowly increase your endurance by increasing the amount of time that you spend doing the activity and always include adequate rest periods.

This activity – rest cycle is not a cure for pain. It is a simple method that has been shown to improve the quality of life for many individuals with SCI. Pacing of activities should work for you if you stick to it. But it is important to always talk to your doctor before you try any new treatment.

**Pressure sores** are probably the biggest reason that individuals with SCI miss work. The best way to avoid pressure sores is to take preventive action.

1. Use a properly adjusted seat cushion that fits both you and your chair.
2. Do a 20 second pressure relief at least every 20 minutes while you are sitting.
3. Sleep on a mattress that offers support, protect pressure areas with soft pillows or sheepskin, and change position regularly while you sleep. Keep your skin clean and dry.
4. Eat a well balanced diet that includes foods that are high in protein, vitamins, and minerals.
5. Drink between 8 and 10 eight ounce glasses of water per day.
6. Avoid all movements or activities that may rub or cut your skin.
7. Do not smoke!
8. Wear loose clothes, shoes and avoid pants with thick seams, buttons, or zippers.
9. Check your skin twice a day to look for a red spot and test for warm skin. If you have redness that does not go away within 30 minutes after you take the weight off of the pressure area, call your doctor as soon as possible.

If you have a skin problem, talk to your doctor about treatment. Your treatment option can range from staying off of the pressure area to surgery.

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Information on **Pain** was provided by John D. Putzke, PhD, a research postdoctoral fellow with the UAB Department of Physical Medicine and Rehabilitation.

Information on **Pressure Sores** was taken from SCI Infosheet #13, *Preventing Pressure Sores*, Developed by Peg Hale, RN, CRRN and Linda Lindsey, MEd, 1998.

SCI InoSheets on Pressure Sores and Pain are available FREE at www.spinalcord.uab.edu or call 205-934-3283.
INCENTIVES TO GET YOU WORKING

It is easier than ever for individuals with disabilities to work. The Social Security Administration (SSA) is now offering improved incentives to get you working.

Cash benefits while you work - You can work a 9-month trial period without losing your regular monthly Social Security check and Medicare insurance benefits. This trial period does not have to occur in 9 straight months. It can be a total of 9 months over a 60-month period. When the trial period ends, your income is reviewed to see if you have reached “substantial” earnings. Substantial earnings for most individuals are when gross earnings for a full or part-time job average $700 per month. For individuals who are blind, the substantial earnings amount is $1170 per month.

Here is an example of this incentive. You take a job earning $1000 per month. You work for 3 months but leave the job because you cannot do the work. However, your monthly benefits continue while you work and after you leave. A year later, you find a job that you can do. You work for another 6 months and earn $1000 per month, still without losing any benefits. Now you have worked a trial period of a total of 9 months over a 2 year period while getting regular Social Security and Medicare benefits. If you continue to work, you will be evaluated by SSA to see if your gross earnings are considered substantial.

Help with other work expenses – Your earnings may not be considered substantial even if you earn more than $700 per month. You can deduct the cost of any item or service that you need to work. These deductible expenses can also be useful in daily living. You may be able to deduct the cost of a wheelchair, personal care attendant (PCA), prescription drugs, any specialized work equipment, or transportation to and from work under certain conditions.

Here is an example. Your trial work period is over. Your gross monthly income is $1000 per month. You pay $400 per month for a PCA. The cost for your PCA can be subtracted from your gross earnings. Your adjusted, or counted, earnings are only $600 per month, which is below the substantial earnings amount of $700. This means you keep regular monthly benefits for at least 36 months, as long as your counted earnings are less than $700 per month.

You will lose your Social Security check if your counted earnings are $700 or more. But you can receive a check for any month that your counted earnings drop below $700 per month if it occurs within 36 months after the 9-month trial period ends.

Medicare while you work – You can keep your insurance no matter how much money you earn. Your Medicare insurance covers you during your 9-month trial period and continues for at least another 39 months. On October 1, 2000 this coverage will expand an additional 54 months for a total of 102 months. This is over 8 years of insurance coverage after you start working. After that time, you can pay a monthly fee to keep your Medicare insurance coverage. This means that you can work and keep your insurance as long as you have a disability.

Some individuals with very little income may qualify to have their state pay the Medicare fee, deductibles, coinsurance cases and other “out-of-pocket” expenses. Check with your local Social Security office to see if you qualify.

Leaving your job – You only need to call your local Social Security office to re-start your monthly Social Security check if you stop working within 36 months after your trial work period ends. There is no waiting period and no need to re-apply. You have to re-apply for benefits following both the trial work period and the 36 months after the trial period. If your new application is approved, you are entitled to another 9-month trial work period and incentives.

Another incentive starts on January 1, 2001. For 5 years after both the trial work period and the 36 months, you will get 6 months of benefits while your claim is being processed. These payments will not have to be paid back if you no longer qualify for benefits.

These incentives can change. Call your local Social Security office with questions about benefits. The SSA is working to improve the way individuals with disabilities get answers to questions about benefits. An Employment Support Representative will be available after January 1, 2001 to provide more consistent, accurate information about Social Security and Supplemental Security Income (SSI) benefits.

Note

Incentives to Get You Working was written by the editor with factual assistance from John A. Roberts, Rehabilitation Specialist, Social Security Disability Programs, Alabama Department of Rehabilitation Services.
Perhaps because only 20% of individuals with spinal cord injury (SCI) are women, information on specific gynecological, menopausal, sexual, and obstetrical concerns have evolved slowly. This is Part 2 of updates on a self-reported study documenting these unique reproductive health concerns. 472 women with SCI were interviewed. The average age of those interviewed was 40, and their average age at the time of injury was 32. Participants in the study were demographically similar to previously published data on age of injury, level of injury, extent of injury and bladder management methods after SCI.

Sexual Behavior

Sexual Intercourse: 87% of all women pre-injury (before SCI) and 67% of all women post-injury (after SCI) reported participating in sexual intercourse. The duration and level of injury was a significant predictor of sexual intercourse post-injury. 49% of women 1 year post-injury, 65% 2 - 10 years, and 76% of women 11 years or more post-injury reported participating in sexual activity. Also, 62% of women with cervical injury, 70% with thoracic injury, and 82% of women with lumbar/sacral injury reported participating. The extent of injury (complete or incomplete) was not a significant predictor of participation in sexual intercourse.

Problems: Problems reported by all women while engaging in sexual intercourse were compounded after injury. Autonomic dysreflexia (AD) and bladder incontinence are complications that differ depending on level of injury. 18.9% of women with cervical injury, 5.8% of thoracic injury, and 7.1% of women with lumbar/sacral injury reported problems with AD while participating in sexual activity. Similarly, 12% of women with cervical injury, 21.9% of thoracic injury, and 7.1% of women with lumbar/sacral injury reported problems with bladder incontinence while participating. 12.4% of women who were 11 years or more post-injury reported a problem during intercourse with foley catheters when compared to 3.1% of women who were less than 11 years post-injury.

Orgasm: 79.1% of all women responding reported experiencing orgasm pre-injury, and 37.3% reported experiencing orgasm post-injury. Among women who were sexually active post-injury, 54.2% reported experiencing orgasm. In this same group, 71% reported experiencing pleasure above the level of injury during sexual activity, 29.6% reported extra genital pleasure without orgasm, and 41.4% reported extra genital pleasure with orgasm. Additionally, 12.8% of women post-injury reported experiencing orgasm without extra genital pleasure, and 16.2% reported neither extra genital pleasure nor orgasm.

Birth Control: 70.3% of women who were sexually active post-injury reported using various methods of birth control, while the remaining 29.7% reported using no birth control. There were no statistically different methods of birth control reported by women pre- and post-injury.

Obstetrical Experience

Pregnancy: 52.1% of women reported at least one pregnancy pre-injury with an average of 2.7 pregnancies per woman. The percentage of women who reported at least one pregnancy post-injury fell to 13.9% with an average of 1.53 pregnancies per woman. A majority of women (63.5%) post-injury became pregnant for the first time, which represented 8.9% of all women who reported at least one pregnancy. 36.4% of women who reported pregnancy post-injury had had a pregnancy pre-injury. 29.3% of women reported having had only one pregnancy before injury compared to 60.6% of women with SCI. Pregnancy outcome trends were interesting. 78% of all women reported giving live births. However, there were a reported 12.7% of miscarriages before injury compared to 6% after injury. The frequency of abortion was 6.5% pre-injury and 14% post-injury.

Note


*Part 1 of this study appeared in the last Research Update and included gynecological and menopausal issues.
Complications: 45.5% of women post-injury reported complications with urinary tract infection (UTI) during pregnancy compared to 8.2% pre-injury. 75% of women with SCI reported at least one complication during pregnancy, which was statistically greater than reported by women pre-injury (49.8%). Other complications exclusive to women with SCI included AD (12%), pressure ulcers (6%) and increased spasticity (12%). About 11% of women post-injury reported having difficulty with transferring near the end of pregnancy, and 4.5% reported to no longer be able to push a wheelchair. 15% of women reported having added leakage around their indwelling catheter, and 9.1% reported having an onset of significant bladder spasms that actually expelled the catheter. 27.3% of women on intermittent catheterization reported a more frequent need to catheterize, and about 25% reported a change in bladder management.

Labor and Delivery: 62% of women pre-injury experienced typical labor symptoms of uterine contraction, labor pains, and/or rupture of the membranes. Women with SCI reported symptoms such as pain above the level of injury (41%), abnormal pain (29%), ruptured membranes (53%), increased spasticity (15%), AD (18%), and increased bladder spasms (17%). Some women with SCI reported normal symptoms during labor, and some reported having no sensation. 62% of women reported a higher frequency of spontaneous vaginal delivery pre-injury compared to 48% of women with SCI. In addition, women with SCI reported more frequent c-section and forceps or vacuum delivery. 1.9% of women pre-injury and 4% of women post-injury reported breech presentation. Women with SCI reported having more problems with blood pressure instability during delivery than women pre-injury. Women with SCI also reported an increase in frequency of premature (prior to 36 weeks gestation) labor and delivery.

Baby at Birth: Pregnancies post-injury were more likely to produce non-premature low birth weight babies of less than 5 lbs 6 oz. There was a trend for women with SCI to have infants that have difficulty breathing at birth. Although not statistically significant, other problems of the baby at birth reported by women with SCI included the baby having a fever, the need for a blood transfusion, or jaundice.

Breast Feeding: 28% of women pre-injury reported breast-feeding their babies compared to only about 11% post-injury.

Conclusion

This study serves as a description of the unique reproductive health concerns of women pre- and post-spinal cord injury. Although the complete consequences and effects of injury are still unknown, some health concerns may be more problematic for women with spinal cord injury.
Cranberry Pills vs. UTIs! - Volunteers are needed for a study to determine whether the antibacterial effects of cranberry pills can reduce the number of symptomatic urinary tract infections in persons with SCI. Bladder management must be condom or ICP to participate. For more information call 205-934-0355.

Pneumococcal Vaccine Study Needs Volunteers - This study is determining the percentage of persons with SCI who maintain protection against pneumococcal pneumonia and the extent that revaccination increases protection. For more information call 205-934-0355.

Pushin' On is also available on the SCI Information Network web site at www.spinalcord.uab.edu and the Fax Information System at 205-975-8376. Call from your phone/fax machine and follow the voice menu options to receive various SCI related material.

Study on Bowel Function Improvement - This study is to determine if 3 injections per week of a new drug can help individuals with SCI have regular bowel movements without the use of suppositories, digital stimulation, or other usual methods of stimulation. Injections are given at home, but participants will be need to visit UAB Outpatient Clinic once every 2 weeks. Call 205-934-9494 for more information.

Pain Treatment - UAB is seeking volunteers for a clinical trial for the treatment of pain among individuals with spinal cord injury. Payment for participation is available with free evaluation and medication. For more details contact John Putzke, PhD, 205-934-3454, Email: Putzke@UAB.EDU

SCI Email Distribution - Receive a notice via email as new and updated SCI material from UAB becomes available; email scirtc@sun.rehabm.uab.edu and type, "subscribe to SCI email distribution list."

Web Resources

- www.worksupport.com/
- www.ssa.gov/pubs/10095.html
- www.ssa.gov/work/index2.html
- www.csun.edu/~sp20558/dis/shcontents.html
- www.disabilityresources.org/VOC-REHAB.html
- www.spinalcord.uab.edu/show.asp?durki=30032
- www.bgsu.edu/offices/careers/process/process.html
- www.disabilityresources.org/EMPLOYMENT.html
- www50.pcepd.gov/pcepd/archives/pubs/ek97/element.htm

Resources

- www.bhawd.org/
- www.bcm.tmc.edu/crowd/
- www.4woman.gov/wwd/index.htm
- www.windowonwellness.com/current/home/
- pw2.netcom.com/~jpender1/default_index.html

School

- www.fastweb.com
- www.ed.gov/prog_info/SFA/StudentGuide/
- www.collegenet.com/
- www.finaid.org/

Book

Job Search Handbook for People with Disabilities by D. Ryan, JIST Publishing, 2000, $16.95 (item code JSHF). To order call 715-232-1342, or write The Rehabilitation Resource, 152 VR Building, University of Wisconsin-Stout, P.O. Box 790, Menomonie, WI 54751, or go to www.chd.uwstout.edu/svri/pwi/trr/trr.html

Women's Issues

- www.bhawd.org/
- www.bcm.tmc.edu/crowd/
- www.4woman.gov/wwd/index.htm
- www.windowonwellness.com/current/home/
- pw2.netcom.com/~jpender1/default_index.html

School

- www.fastweb.com
- www.ed.gov/prog_info/SFA/StudentGuide/
- www.collegenet.com/
- www.finaid.org/

RRTC Training Office
UAB-Spain Rehabilitation Center
619 19TH STREET SOUTH - SRC 529
BIRMINGHAM, AL 35249-7330

RETURN SERVICE REQUESTED