

# Survivor's Guide to Overcoming Disability Barriers

**A Guide to Overcoming Barriers  
to Employment and Housing  
and  
Obtaining the Benefits You Need**



Published by

**Vermont Protection & Advocacy, Inc.**

Federally mandated as the Protection & Advocacy system for Vermont. Our mission is to promote the equality, dignity, and self determination of people with disabilities.

Originally published September 2006  
Updated Edition Published July 2009

This publication was made possible by funding from The Social Security Administration (SSA). SSA has reviewed this publication for technical accuracy only, this should not be considered an official SSA document.



Published by

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# Introduction

by Ed Paquin, Executive Director, VP&A

In November of 2003 an exciting and motivated group of people with disabilities came together to share their personal stories, their sources of strength and their tricks-of-the-trade for living with disabilities.

They were supported and encouraged by staff of Vermont Protection & Advocacy and the Vermont Center for Independent Living, largely folks with disabilities themselves. I was privileged to be a part of this effort.

In late 1988 a contact with a high voltage wire brought me into company with the one fifth of our population who live with disability. It didn't change who I am, but it certainly changed how I live and perhaps more importantly it changed the world I lived in by the different way the world looked at me. The challenges I face may not be different in kind from those faced by others, but there is no extracting disability from the realities of my day-to-day life.

Whether we are born with disability, injured, or affected by disease or age, we live in a world that only partially understands that disability is, as stated in the ADA, "a natural part of life." Society patronizes, ignores or even ostracizes people with disabilities. Employers overlook ability. Housing, transportation, our basic activities of daily living and even our family and social relationships can be profoundly affected. We live in a world that must still profoundly change if it is to be a world free of discrimination. This is a serious social and political challenge.

But we must change as well!! We live in the world we live in, and if we are to live with success and happiness we must make our way through it even as we try to affect change.

What we hope to show in this manual is that our journey to fulfillment need not be made in a vacuum or without support. The people with disabilities who contributed to this book hope to share our life experience and the resources that have made our paths a little easier. We hope that our stories and the systems described in this guide are a help as you navigate over, around and through the barriers that you face.

Be sure of one thing: you are in excellent company!!

## ACKNOWLEDGEMENTS

Vermont Protection and Advocacy, Inc. wishes to thank the following individuals and organizations for assisting with the project. Without the hard work and positive attitudes of these people, the Survivor's Guide would not have been possible.

Sheri Arpin	Jules Negri
Claire Benoit	Ed Paquin
Nicole Brothers	Rita Phelps
Cynthia Brown	Merry Postemski
Ronnie Ciambra	Nancy Poulin
Christina Colombe	AJ Ruben
Alora Grooms	Runaway Dog
Bethany Krampetz	Kathleen Russo
Lisa Larson	Gary Salter
Jay Layfayette	Matt Saltis
Larry Lewak	Renee Sheltra
Deborah Lisi-Baker	Stowe Flake Mountain Resort and Spa
Gayle Lyman	Gail Warner
Liz Manfredi	Elizabeth Ann Wilson
Lynne Metz-Schwartz	Bob Zingher

VP&A gratefully acknowledges the support of the SSA in making this publication possible.

# Table of Contents

Chapter	Page
<b>1. Disability and the Law</b>	<b>7</b>
<b>2. Your Employment Rights</b>	<b>12</b>
<b>3. Housing Discrimination</b>	<b>19</b>
<b>4. SSI and SSDI Made Easy</b>	<b>25</b>
<b>5. Overpayments</b>	<b>43</b>
<b>6. Work Incentives and Ticket to Work</b>	<b>47</b>
<b>7. Medicaid and Medicare</b>	<b>53</b>
<b>8. PABSS- Protection and Advocacy for Beneficiaries of Social Security</b>	<b>59</b>
<b>9. State of Vermont Independent Living Services: VocRehab, Attendant Care Services, Reach Up, Choices for Care</b>	<b>60</b>
<b>10. Personal Stories</b>	<b>68</b>
<b>11. Appendix – Guide to Resources</b>	<b>95</b>

**“Just because you are disabled doesn’t  
mean that you have to give up.**

**You can still DO! Believe in yourself.”**

**– Nancy**

**VP&A**

# **Survivor's Guide to Overcoming Disability Barriers**

**A Guide to Overcoming Barriers  
to Employment and Housing  
& Obtaining the Benefits You Need**

# I. Disability and the Law

## What is the legal definition of disability?

## Who is considered “disabled” under the law?

The Americans with Disabilities Act of 1990 (ADA) gives civil rights protections to individuals with disabilities similar to those provided to individuals on the basis of race, color, sex, national origin, age, and religion.

The ADA provides these civil rights protections to any citizen whose physical or mental disability significantly limits his or her major life activities. A major life activity is a function that most people can do with little or no difficulty such as seeing, hearing, speaking, walking, learning, thinking, and caring for oneself.

## The ADA covers more than just people who are deaf, blind or who use wheelchairs:

- People who have chronic physical conditions such as epilepsy, diabetes, HIV, severe arthritis or carpal tunnel syndrome may be covered under the ADA.
- People with psychiatric impairments such as major depression, bipolar disorder and post-traumatic stress disorder may also be covered under the ADA.
- People with traumatic brain injury, learning disabilities or developmental disabilities are also protected under the ADA.

The ADA also protects people from being discriminated against if they have a history of being disabled. For example, if you had cancer but are now in remission, an employer can't refuse to hire you because he/she is afraid your cancer will return. Or, if you have had a history of mental illness, you can't be discriminated against.

## What exactly are my rights under the ADA?

THE AMERICANS WITH DISABILITIES ACT of 1990 (ADA):

- Makes it illegal for private employers or state government to discriminate against people with disabilities in recruitment, hiring, promotions, training, pay, social activities, and other privileges of employment.
- State and local governments must give people with disabilities an equal opportunity to access and benefit from all of their programs, services, and activities (e.g. public education, employment, transportation, recreation, health care, social services, courts, voting, and town meetings).
- Businesses that offer public accommodations (such as restaurants, stores, hotels, movie theaters, private schools, doctors' offices, and bus lines), as well as nonprofits that offer public services (such as day care centers, homeless shelters and recreation facilities), must make their programs accessible to people with disabilities, too.
- Telephone companies must establish and maintain telecommunications relay services (TRS) for people who are deaf, hard of hearing, and who have speech impairments, staffed 24 hours a day, 7 days a week.

**“Don’t give up. Put yourself out there.  
Everybody has something to contribute.  
Find your interest...something that  
really moves you. Don’t be put off  
by people who look at you with  
non-compassionate, confused and  
patronizing eyes. Being disabled  
doesn’t mean you can’t participate.  
Don’t be afraid to ask for help.”  
– Elizabeth Ann**



## What other federal and state laws protect people with disabilities?

THE REHABILITATION ACT OF 1972 makes it illegal for employers and contractors who do business with the federal government to discriminate against persons with disabilities in employment practices, providing public services, access to facilities, or in their communication practices.

THE TELECOMMUNICATIONS ACT OF 1996 requires that communications equipment and services, such as telephones, cell phones, pagers, call-waiting, and operator services, be made fully accessible to people with disabilities.

THE FAIR HOUSING ACT OF 1988 prohibits housing discrimination on the basis of disability. It is unlawful to discriminate in any aspect of selling or renting housing or to deny a dwelling to a buyer or renter because of the disability of that individual, or an individual who intends to live in the residence.

THE VOTING ACCESSIBILITY FOR THE ELDERLY AND HANDICAPPED ACT and the HELP AMERICA VOTE ACT (HAVA) OF 2002 require polling places for federal elections to be physically accessible to people with disabilities.

VERMONT STATE LAWS make it illegal for any school, employer, employment agency or labor organization to discriminate against somebody because of their race, color, religion, ancestry, national origin, sex, sexual orientation, place of birth, or age or against a qualified individual with a disability.

**Note:** these are just some of the laws that prohibit discrimination based upon a person's disability. If you have questions about your rights, see the Resources section in the Appendix.

**“You’re not a failure because one job didn’t work out. Learn the lesson, whatever it is you need, and move on.”**

**– Participant**

**My partner has AIDS. Is there anything to protect me from being discriminated against?**

YES. People who are associated with somebody with a disability are protected under the ADA.

**I'm not disabled, really. But I was born with birth defects, so people often think I am disabled. Am I protected under the ADA?**

YES. The ADA protects people who are treated or perceived as having a disability—even if they don't identify to others as having a disability.

**Jay's advice for those interested in becoming employed is this:**

**“Disability shouldn't stop you from what you want to do. Get into an employment program like CAP.\* Get involved—in programs, with advocates, and in the community.”**

**– Jay**

**\*Community Access Program**

## ANN'S STORY:

Ann's first symptoms of MS appeared at the age of 28. She experienced fatigue and difficulty with sitting or standing for too long. She was diagnosed with MS at that time, but didn't believe in the diagnosis because her symptoms went into remission for several years. When they re-appeared, when she lost the use of her left eye and had discomfort in the right side of her body, she continued to disbelieve she had MS. She began to walk with a limp, and told people she'd had a skiing accident. Her friends confronted her, and she slowly began to come to terms with the diagnosis. She recalls how deeply in denial she was at the time, and how extremely difficult it was for her to accept her illness. For 25 years, she was in denial.

Ann felt tremendous rage at the fact that she had MS. Before onset, she was a vibrant, strong and independent woman who didn't make it a habit to depend on people. She went through incredibly difficult inner work dealing with her fear, loss and finding the strength to continue.

Proclaiming, "I have MS" were the words that helped Ann feel liberated. It was a real breakthrough. Later, she started a support group for others struggling with MS. Although she was disillusioned by the process, and was discouraged that so many others also felt depressed, she continues to gain support from her friends and family, and continues to be an active member of her community.

# 2. Your Employment Rights

VP&A

12

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## What are my employment rights under the ADA?

The ADA protects you from discrimination in all employment practices, including: job application procedures, hiring, firing, training, pay, promotion, benefits, and leave. You also have a right to be free from harassment because of your disability. An employer may not fire or discipline you for asserting your rights under the ADA. Most importantly, you have a right to request a reasonable accommodation for the hiring process and on the job.

## What is disability discrimination in employment?

Disability discrimination means treating individuals differently in the work place because of their disability, perceived disability, or association with someone who has a disability. Some examples of discrimination include:

- **DISCRIMINATING** because of a physical or psychiatric/mental disability in all employment related activities, such as hiring, firing, promotions, job assignments, pay, benefits, and leave time.
- **HARASSING** an employee because of his/her disability
- **ASKING QUESTIONS** about your disability or medical condition on a written application, during an interview or at any time during the application process, or requiring only you to have a psychiatric or medical exam, if no one else is required to.
- **CREATING OR MAINTAINING** physical barriers that interfere with the movement of people with physical disabilities
- **REFUSING** to provide a reasonable accommodation to employees with physical or psychiatric disabilities that would allow them to work.

**Kathleen said that she was treated differently and believes she was passed over for a full-time employment opportunity. She believed her employers were wondering if she “could really deal with” the pressures of full time employment given the fact that she was engaged in mental health treatment.**

**“I had the impression that they didn’t want to offer health insurance to someone with my physical and mental health disabilities and that they didn’t want to deal with someone going to Rutland Mental Health.”  
– Kathleen**

**Do all employers have to follow the law?**

All employers with 15 or more employees are required to follow the Federal law (the ADA). Under Vermont law, any employer, no matter how many employees it has, is not allowed to discriminate against an employee because of the employee’s disability.

**Can I be asked about my disability in a job interview?**

NO. However, an employer can ask you if you can perform the job duties with or without a reasonable accommodation. An employer cannot refuse to hire you because you need an accommodation to do the job.

**Can I be forced to take a medical exam?**

NO, not before you are offered the job. If you have been offered a job, the employer can require that you take a job-related medical exam as long as ALL new employees have to take it. You can’t be singled out (required to take the exam) just BECAUSE of your disability.

## **Does an employer have to hire me just because I am person with a disability?**

NO. Having a disability does not give you any more rights than non-disabled people. You must have the necessary qualifications, education, skills, or licenses to perform the job duties. You must be able to do the job with or without a reasonable accommodation.

VP&A

14

### **What is a reasonable accommodation?**

A reasonable accommodation is a change or adjustment to a job or worksite that makes it possible for a qualified person to do the job.

You may request an accommodation at any time during the application process or any time before or after you start working.

2.

### **What are examples of reasonable accommodations?**

Some of the most common requests for accommodations include, but are not limited to:

- making the work site accessible
- modifying work schedules
- providing special equipment or assistive devices
- providing readers or interpreters
- allowing time off for treatment
- personal care assistants

**“My employer was not as understanding [about the need to supply accommodations] as you would expect them to be, especially because they were a mental health agency. It was as if they were unaware. Although once they ‘became aware they were as helpful as they could be.’”**

**– Gary**

## How do I get an accommodation? You have to ask for it! HERE'S HOW:

1. You must tell your employer you are a person with a disability.
2. State that you are requesting a reasonable accommodation under the ADA (or Rehab Act if you're a federal employee).
3. Identify the problems with the job task.
4. Explain what you want for an accommodation.
5. Invite your employer's accommodation ideas.
6. Ask your employer to respond to your request in a reasonable amount of time.

VP&A

15

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**I'm reluctant to tell my employer about my disability because I don't want to reveal its cause (for example, AIDS or substance abuse). If they ask how I became disabled, do I have to tell them?**

NO. The only information you must provide is the medical name for your disability, and how it's related to your need for accommodation. You do not need to share any other confidential personal information in connection with this type of request.

**“Show your talents. Let an employer know that despite disability, you can do the job.”**

**– Sheri**

On the following page, we have provided a sample letter to an employer, which includes all the important points. In your own letter, be sure to:

- describe how your disability affects your capacity to do the job, and
- request accommodations that are reasonable and appropriate to address your disability, in relation to the job tasks expected of you.

## Sample Accommodation Request Letter

VP&A

16

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101 Turning Point Drive  
Burlington, Vermont 05401  
March 8, 2008

Mr. John Smith, Human Resources  
Company B  
63 Main Street  
Burlington, Vermont 05401

Dear Mr. Smith:

I have been a data entry clerk with Company B Inc. for the past 7 months. I also have a condition called diabetes mellitus, more commonly known as Type I diabetes. I informed the company of my condition when I applied for my current position. I have attached medical records documenting my disability.

I am writing this letter to request a job accommodation, under provisions established by the Americans with Disabilities Act of 1990. As a result of my condition, I have started to experience problems with my vision. Specifically, it has become increasingly difficult for me to read or to look at my computer screen. This limitation is affecting my performance, as I enter all assigned data into a computer system.

I believe that my situation can be accommodated with relative ease and little expense. A glare filter attached to my computer screen would reduce the amount of glare and eyestrain. Additional lighting in the room in which I work would also help.

Any of your ideas on how to accommodate my situation would be greatly appreciated. Please feel free to call, write or email me with your suggestions at any time. I do ask, though, that you respond to my request within two weeks. I would like to resolve my situation and return to my previous performance level as soon as possible.

Sincerely,

(Your signature)

Your printed name

Enclosure: documentation of disability



### **Does my request have to be in writing?**

NO. You can make a verbal request for an accommodation. But it is best to put your request in writing to create a 'paper trail,' in case there are any problems.

### **Can somebody request one for me on my behalf?**

YES. Anybody can request a reasonable accommodation for you such as physicians, case managers, advocates, parents, a friend, partner or spouse.

### **What happens after I make a request for a reasonable accommodation?**

Once you have made your request, the employer should discuss available options with you. If you have a disability that is not obvious, the employer may request documentation from you, such as a letter from your doctor, explaining why you need accommodation. You and the employer should work together to determine an appropriate solution.

### **Does my employer have to give me what I ask for?**

NOT ALWAYS. An employer does not have to provide a given accommodation if it can prove that providing it will cause a huge burden or expense. An employer may not give you exactly what you are asking for, but may have other ideas about accommodating your needs.

### **What if my employer refuses to provide me with a reasonable accommodation?**

1. Gather as much documentation of your original request for an accommodation as you can, as well as any response your employer made in writing; then
2. Contact one of the agencies listed at the end of this chapter for assistance.

**Can money be taken out of my earnings, or can I be paid a lower salary, to cover the cost of the accommodation provided by an employer?**

NO.

**VP&A**

**18**

**Who can help me if I believe I am being discriminated against?**

- Human Rights Commission 1-800-416-2010 (voice / TTY)
- Vermont Protection & Advocacy 1-800-834-7890
- Attorney General Civil Rights Unit 1-802-828-3171
- Equal Employment Opportunity Commission 1-800-669-4000

(See Appendix for mailing addresses for agencies listed in this book.)

**2.**

### **JAY'S STORY, Part I:**

Jay's world was turned upside down at the age of 6 when he was a passenger in a horrific car accident that killed the driver of the car—his mother. Following high school, Jay utilized the services of CAP's employment support programs to find and maintain employment. He has held a variety of positions, most recently in the landscaping and construction fields.

Although Jay receives SSDI benefits, his reasons for working are twofold: "for the extra money and because I get bored and depressed when I'm not working." As for being a person who has a disability attempting to find or maintain employment, Jay says that he has not been discriminated against, partly because the CAP workers partner with employers who are willing to be involved in a supported employment program and partly because he doesn't talk about his disability much on the job site.

# 3. Housing Discrimination

## What is housing discrimination?

It is being denied access to housing or otherwise treated unfairly because of your:

- disability (including HIV/AIDS)
- race
- sex
- sexual orientation
- age
- marital status
- religion
- color
- national origin
- having children
- receiving public assistance

VP&A

19

3.

**HOUSING DISCRIMINATION IS ILLEGAL!!!**

**“I lived in an apartment my employer owned. Part of my job was managing the building and supporting the residents. Since I was no longer working, my employer asked me to move out so someone else could take over.”**

**– Gary**

## How do landlords discriminate against people with disabilities?

Often it is subtle. Landlords rarely say, “you can’t live here because you are disabled.” However, they might say things like:

- Your wheelchair is going to damage the walls, carpet, floors, etc.
- We don’t rent to people who are on welfare.
- I’d like to rent to you, but my insurance will go up.
- We have a “no pets” rule, including your service animal.
- We can’t have mentally disabled people here, it will disturb the neighbors.
- I don’t really want all those changes (like a grab bar and a ramp) here.
- I can’t risk having you here. You’re deaf and won’t hear the fire alarm if it goes off.
- Have your psychiatrist call me, then I’ll let you know.

## Who is protected from discrimination?

According to the federal Fair Housing Act of 1988, a person who is disabled:

- has a physical or mental impairment which interferes with at least one major life activity (walking, speaking, thinking, seeing, learning, breathing, caring for oneself, hearing, etc.)
- has a record of physical or mental impairment
- is perceived by others to have a mental or physical disability

## What is a reasonable accommodation?

A reasonable accommodation is a change in any rule, policy, procedure or service that will allow a person with a disability to access, use and enjoy his or her housing the same as someone without a disability.

## What are some examples of reasonable accommodations?

- building a ramp to the building's entrance
- letting you out of your lease early if you have to move because of your disability
- installing support bars in the bathroom
- allowing service animals

## Who has to pay for my accommodations?

If the home is privately owned and you do not benefit from a public housing subsidy, you do. However, if a landlord receives federal funding, such as rental subsidy through the Section 8 program, then he/she has to pay for it. You may wish to contact the Home Access Program at 1-800-639-1522 for information about funding and tax incentives for home access accommodations.

## How do I get a housing accommodation?

You don't need to make your request in writing, but it is a good idea to do so. In a letter to your landlord, include the following:

- State you are a person with a disability (you have to say what your disability is).
- Say you are requesting a reasonable accommodation under the Fair Housing laws.
- Write down, or tell your landlord, the problem you're having.
- Explain what you want for an accommodation and what you plan to do.

**Note:** Always keep copies of your letters. If you talk to your landlord about this, write down the date, time and what was said.

## **Does my landlord have a right to ask for proof that I need an accommodation?**

YES. The landlord can ask you to have a service provider verify that you need an accommodation.

Examples of service providers are your doctor, therapist, adaptive equipment specialist, or a staff member at a community mental health agency.

Your service provider does not need to reveal the source of your disability — only what it is, and how its effects result in the need for a specific accommodation.

## **Do all landlords have to follow the rules?**

NO. There are a few exceptions:

- houses that have three or less apartments AND the landlord or member of the landlord's family, lives in one of the apartments
- houses or apartments that are owned by religious organizations
- if you are under age 18

## **My landlord is willing to modify the apartment to meet my needs, but says he cannot afford the full cost of the work at this time. Are there any resources available to help?**

YES. Here are three options:

1. The ENABLE LOAN PROGRAM of the Vermont State Housing Authority can help with the costs of making your housing accessible. Call them at 1-800-820-5119 (voice) 1-800-798-3118 (TTY).
2. HOME ACCESSIBILITY PROGRAM helps Vermonters who have a disability. Grants are based on household income and are limited to making bathrooms and the main entrance to the home accessible. Call the Vermont Center for Independent Living at 1-800-639-1522 (voice/TTY) for more information.

3. Some municipalities and nonprofit agencies have funding available to help their residents and/or clients install needed home modifications. Your local Area Agency on Aging (call 1-800-642-5119) is a good place to learn about the possibilities from these sources.

**What can I do if I believe I have been discriminated against, or have been refused a reasonable accommodation?**

**VP&A**

**23**

The following organizations can help:

- The CVOEO Fair Housing Project      1-800-287-7971 (voice/TDD)
- Vermont Center for Independent Living      1-800-639-1522 (voice/TTY)
- Vermont Human Rights Commission      1-800-416-2010 (voice/TTY)
- Vermont Legal Aid      1-800-889-2047 (voice/TTY)
- Vermont Protection & Advocacy      1-800-834-7890

**3.**

**PARTICIPANT'S STORY:**

[Participant] has a psychiatric disability of Bi-Polar. She grew up in Vermont in the 60's and had a non-traditional education. Although she admits to memory loss and concentration difficulties, she is nevertheless an intelligent woman with a lot of perseverance. Her need to feel useful in the world is evident and admirable.

She had suicidal thoughts after her dad's death and was hospitalized. The nurse manager she worked with was very understanding, and [Participant] worked her way back to being a charge nurse. Although she was successful in her job, she felt stressed by it and was having a hard time holding it together. A psychiatrist helped her get a part-time position, but there were no concessions made on her behalf.

In 1997 she took a drug over-dose which left her feeling like she could not return to work. She recounts this memory as an awful time for her. Her kids were there and rescued her.

She decided not to keep her nursing license current because she felt she couldn't handle it at the time. So she decided to weave, and continue therapy. She felt a lot of fear during this time of reflection after her attempted over-dose. She was afraid of being in public for awhile and her energy level was low.

She returned to work a year ago. She started slow, with a part-time job at a small Co-Op in Vermont. She is a driver for Vermont Center for Independent Living (VCIL) and helps people with other disabilities to get around the community. She also worked the switchboard at VCIL. She currently lives in a household of people with other disabilities, teaches music and prepares basic meals.

She responds with great clarity about the need for exploration and trial and error when it comes to employment. "You're not a failure because one job didn't work out. Learn the lesson, whatever it is you need, and move on."



# 4. SSI and SSDI Made Easy

VP&A

25

Because having a disability may make it difficult or impossible to maintain full-time employment or earn sufficient income to meet your needs, several federal programs provide monthly cash benefits to persons with disabilities who qualify. The most important of these programs are SSI and SSDI. This chapter defines each program's eligibility standards, and explains how to apply.

## What is Supplemental Security Income (SSI)?

This is a monthly cash benefit paid to people with limited income and resources who are disabled, blind, or age 65 or older. Blind or disabled children can also get SSI benefits.

SSI is not based on your history of prior work. Your eligibility is determined based on disability and financial need.

## Will I Get Health Insurance if I Receive SSI?

In most states, people eligible for SSI automatically qualify for Medicaid. In other states, you must sign up for it.

## What is Social Security Disability Insurance (SSDI)?

A monthly cash benefit paid to people who have worked and paid into this insurance program with their taxes, and who are disabled or blind.

There are no unearned income or asset limitations. Your eligibility for SSDI is based on work history.

4.

**Will I Get Health Insurance if I receive SSDI Benefits?**

Yes, in the form of Medicare. Coverage begins after 24 months of SSDI benefit eligibility. You may also receive Medicare right away if you have chronic renal disease and need a kidney transplant or maintenance dialysis or have Lou Gehrig’s disease (amyotrophic lateral sclerosis).

**Can I Get both SSI and SSDI?**

If your SSDI benefit is small enough, you might qualify for SSI as well.

**How does the Social Security Administration (SSA) define “disability”?**

- For the SSA “disabled” means not being able to work enough to earn at least \$980 per month in 2009. This amount is called “Substantial Gainful Activity” (SGA) and is usually changed by the SSA every year. If you are blind SGA is \$1,640 per month in 2009.
  - Your disability has to have lasted, or be expected to last, at least 12 months;
- or
- Your disability can be expected to result in death.

**SGA for recent years:**

Year	Non-blind	Blind
2006	\$860	\$1,450
2007	\$900	\$1,500
2008	\$940	\$1,570
2009	\$980	\$1640

Contact your local Social Security Office for future changes or visit [www.socialsecurity.gov](http://www.socialsecurity.gov)

## How Do I Apply for SSI or SSDI?

You can call the Social Security Office at 1-800-772-1213 and tell them you want to apply for disability benefits. If you are Deaf or hard of hearing, call 1-800-325-0778.

Social Security will mail you a Disability Starter Kit which should arrive within one week. This kit answers common questions about applying for benefits and includes a worksheet that will help you gather the medical information you need.

You can also apply online at [www.socialsecurity.gov/applyfordisability](http://www.socialsecurity.gov/applyfordisability).

You will be given a date and time to have either a phone interview or an in-person interview.

## Oh No...An Interview !!!?

Relax. This part is a breeze. You will be asked some questions about your work history, income and resources, disabling condition, names and addresses of your doctors and hospital visits, medication, and medical test taken.

This part of the application process is to figure out which benefit program(s) you might be eligible for and to gather disability information about you.

## What happens next?

After you complete your interview and provide or mail in form SSA-827 "Authorization to Disclose Information to SSA", Social Security will review your application and answer two questions:

1. Did you work enough to qualify for SSDI?

and

2. Do you have limited money and assets?

If the answer is NO to both questions, you will get a letter saying you are not eligible for SSI or SSDI.

If the answer is YES to at least one question, your claim will be passed along to another agency who will decide if you are disabled.

## Who decides if I am disabled?

Disability Determination Services is the agency that looks at your medical evidence and prior work experience to decide if you are disabled.

VP&A

28

## What information do they need to find me disabled?

This is a very tough question because the answer is a little bit different for each disability. But some of the basics are the same:

1. You must prove you can't work enough to earn at least \$980 per month for non-blind individuals or \$1,640.00 a month for blind individuals. This is called Substantial Gainful Activity (SGA).
2. You must have a "marked" (significant) impairment in at least TWO of the areas listed below:
  - A) Activities of daily living (shopping, cleaning, taking care of yourself, managing your own money, cooking, etc...)
  - B) Concentration, Persistence and Pace (paying attention, concentrating, finishing tasks or projects in the same amount of time as it would take most people, following directions, remembering)
  - C) Social Functioning (getting along with others, having friends, interacting appropriately with the public, being cooperative with co-workers)
  - D) Episodes of Decompensation (signs or symptoms of your condition get worse when you try to return to work or are in a work-like setting such as school)
3. Under Public Law 104-121 the definition of disability excludes drug addiction or alcoholism as the primary basis for a disability. However, drug and alcohol users who can demonstrate that they are disabled based on conditions other than their drug or alcohol addiction are still eligible for SSI or SSDI.

4.

4.This is the tricky part. Each disability has certain criteria that have to be met. There are far too many to list in this resource manual.

**Note:** If you want the criteria for your disability, you can get it online at: [www.ssa.gov/disability/professionals/bluebook/AdultListings.htm](http://www.ssa.gov/disability/professionals/bluebook/AdultListings.htm)

### What can I do to help the process?

Ask your doctor or treatment provider to write a letter and give it to you to give to Social Security at the time of your interview or send to the Disability Determination Section after your initial interview. .

On the next four pages are two form letters you can use to ask for your provider's help in documenting your claim. They include:

1. A form letter to your treatment provider, to request their help; and
2. A sample letter to enclose with your request letter to this provider.

Some providers may already be familiar with the disability guidelines and requirements for documentation. If your provider follows the format suggested here, these letters will make it more likely that the Social Security Administration will have what they need to process your claim.

### PARTICIPANT A'S STORY, Part I:

[Participant] has a psychiatric disability. In her twenties, she began to become aware of her own repressed memories of abuse that she suffered and worked extensively with a therapist. At 30, she was hospitalized and applied for Disability benefits. Her therapist went to bat for her and helped her receive benefits while she was healing and sorting through her life.

She currently works as a massage therapist. She is hoping to find a mentor to help her with implementing her dreams.

FORM LETTER TO SEND OR GIVE TO YOUR TREATMENT PROVIDER

VP&A

30

4.

\_\_\_\_\_  
Your address line 1

\_\_\_\_\_  
Your address line 2

\_\_\_\_\_  
Date

Re: Disability claim

\_\_\_\_\_  
social security number

Dear \_\_\_\_\_:

I am applying for Social Security Disability benefits. In order for me to be found disabled by Disability Determination Services, we must provide specific medical evidence to satisfy the disability criteria, as listed in the Code of Federal Regulations. I need your help to document evidence of my disability.

The criteria are satisfied when the evidence shows the following:

1. Profound impairment in at least TWO of the following areas:

- A) Activities of Daily Living
- B) Concentration, Persistence, and Pace
- C) Social Functioning
- D) Decompensation in work-like settings

2. Brief discussion of clinical signs or symptoms specific to my condition (i.e. Lupus, Traumatic Brain Injury, Major Depressive Disorder, PTSD, Cancer, HIV, etc. ...)

3. A direct statement indicating that I am not able to engage in substantial gainful activity for AT LEAST ONE YEAR. Substantial gainful activity is defined as having the ability to earn \$980.00 a month in 2009. Work may be substantial even if it is performed on a part-time basis.

I'm asking you to write a letter of support on my behalf for this disability. Please address the information provided above, to the best of your ability. (If I have a psychiatric disability, please include a multi-axial evaluation.)

For your convenience, I am including a sample letter of support.

Please mail your completed report to: Disability Determination Services, 2 Pilgrim Park Road – 2nd Floor, Waterbury, VT 05676. I would appreciate it if you would keep one copy for my chart, as well.

Thank you (in advance) for taking the time to write this letter for me. I truly appreciate your help. I will call you next week to see if you have any questions.

Sincerely,

---

Your name

## SAMPLE LETTER OF SUPPORT FOR SOCIAL SECURITY DISABILITY CLAIM

VP&A

32

4.

Disability Determination Services  
2 Pilgrim Park Road - 2nd Floor  
Waterbury, VT 05676

Dear Disability Determination Services:

This letter is in support of the disability application made by Jane Doe. I have been treating Ms. Doe since November, 1995 for Major Depressive Disorder, Post Traumatic Stress Disorder and Attention Deficit Hyperactivity Disorder. Her psychiatric impairments have caused profound functional limitations in her ability to engage in activities of daily living, social functioning, and in her capacity for concentration, memory and task completion.

In spite of her engagement and compliance with treatment, Ms. Doe's debilitating symptoms continue to persist, rendering her totally disabled. Her current diagnoses are as follows:

Axis I: Major Depressive Episode, recurrent  
Post Traumatic Stress Disorder, acute  
Attention Deficit Hyperactivity Disorder, residual  
type Marijuana Abuse/Dependence, in full remission  
Polysubstance Abuse, in long-term remission

Axis II: Deferred

Axis III: Lower back injury

Axis IV: Severe (legal, mental health issues, financial, lack of social supports, family, recent trauma)

Axis V: 40



Ms. Doe demonstrates a markedly diminished interest in most all activities, psychomotor agitation, loss of appetite and decreased energy. She experiences feelings of excessive and inappropriate guilt and perceives herself as being worthless. She has severe sleep difficulties that have not responded to medication.

Ms. Doe is chronically apprehensive and expects to be harmed. She is unable to concentrate or focus her attention for any length of time, particularly in a work-like activity. She experiences a high level of anxiety and withdraws from interacting with others. She experiences recurrent severe panic attacks at least once a week during which she has rapid heart rate, difficulty breathing, twitching and trembling of her extremities, hyperarousal, a sense of feeling out of control, and a sense of impending doom. Her symptoms also include racing thoughts and immobilization. She experiences intrusive and recurrent memories of traumatic events which escalate her anxiety level and is followed by even more intense withdrawal behavior. At times she is unable to leave her home. The onset of these panic attacks is sudden and unpredictable.

Ms. Doe has a documented history of substance abuse. However, she has not used illegal substances since 1999. Her former drug usage is NOT a contributing factor in the manifestation of her current disabling symptomology.

Based on her profound psychiatric impairments, Jane Doe is unable to engage in substantial gainful activity, and will be unlikely to do so for at least one year.

Please feel free to contact me if I can offer any additional information.

Sincerely,

Dr. Do Good

## How long will it take for Social Security to decide if I am disabled?

The process usually takes between 3-6 months.

## Social Security tells me I'm not disabled and denied me benefits...NOW what do I do?

Call Social Security, or better yet write SSA a letter, and tell them you want to appeal their decision. Ask for a REQUEST for RECONSIDERATION. You will have 60 days to do this. If you miss the 60 day deadline, you will have to re-apply.

When you request a Reconsideration, your application and medical evidence will be given to a different person to decide if you are disabled. If the second person looks at your case and decides you are disabled, you will get your benefits.

## How long will this take?

Usually between 3-6 months. Sometimes longer...sometimes less.

## What if I'm still denied???

Time to talk to the judge!!!

At this point, you need to call, write or meet with Social Security. Tell them you want to appeal their decision and ask for a Hearing with the Administrative Law Judge. You will be sent a form to fill out. Also, you can contact an attorney. Private attorneys take these cases because they can receive attorney's fees if successful. You may also wish to contact Vermont Legal Aid at 1-800-889-2047.

**You have 60 days from the day you receive your denial letter to contact the SSA.**

## When will I get my hearing?

It will often take 12-18 months. But it really depends on how busy the Office of Disability Adjudication and Review (ODAR) is.

## How much notice will I get?

In Disability Service Improvement (DSI) States, which include Vermont, there is at least 75 days notice of the hearing.

## What if I need to reschedule my hearing?

Call the Office of Disability Adjudication and Review immediately at 603-629-9326. They are located in New Hampshire, but handle all Vermont cases.

## Where will it be held?

Within 75 miles from your home. You can be reimbursed for travel if you live more than 75 miles from the hearing.

## Can I bring a lawyer or advocate?

YES. You can ask the Office of Hearings and Appeals to send you a list of attorneys and advocates who may be able to help you.

## Can I bring new medical evidence?

YES.

## Can I bring witnesses?

YES.

## How about friends, can they come along to support me?

Your friends can travel with you. But generally, they will not be allowed in the room during the hearing. If they are witnesses, they will wait in another room until the judge calls for them.

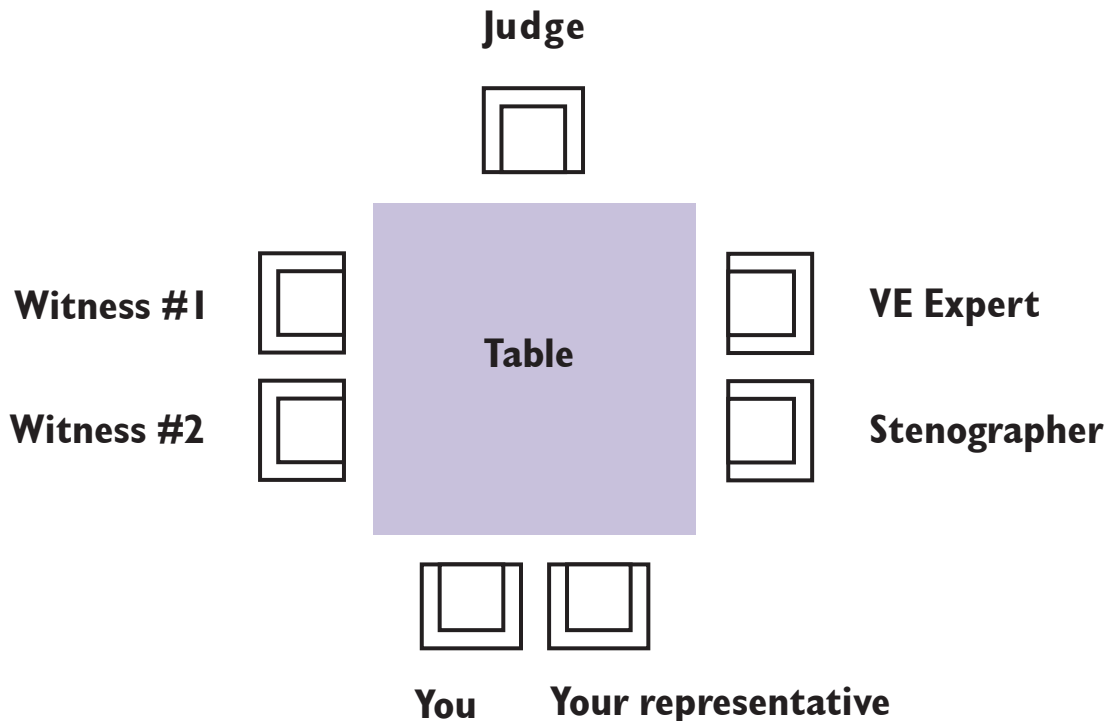
## WHAT CAN I EXPECT AT THE HEARING?

### Who Will Be There?

- The administrative judge will be there.
- A verbatim hearing reporter will attend to record the hearing.
- A vocational expert may be there to answer some questions for the judge.
- You, your representative if you have one, and your witnesses if you have any.

### Will It Take Place In a Courtroom?

NO. The hearing is usually held in a small conference room. The room is generally set up like this (the configuration of the hearing room may differ from hearing office to hearing office):



## What will happen in the hearing?

- A clerk will come out and get you.
- You will be seated at the table.
- You will be placed under oath.
- The judge will tell you what you can expect and ask you if you have any questions.
- Then you will be asked some questions.

## What can I expect at the hearing?

Each judge tends to run things a little differently. Generally, the process goes something like this:

- You are placed under oath. Be truthful! .
- If you have a representative, he/she may be asked a couple of questions and will make an opening statement.
- The judge will ask you if there is any new evidence you want to give him/her.
- Your representative may ask you some questions. Always look at the judge when answering questions. The judge will ask questions if you don't have a representative.
- If you have witnesses, they will be brought in and your representative will ask them questions. The judge might ask questions of them, too.
- If there is a vocational expert present, the judge will ask him/her some questions.
- Sometimes the judge will ask you a few questions.

## What Kinds of Questions Will Be Asked?

Questions will be different depending on your condition and your representative's style. Some examples of the questions you may encounter:

- Are you working at the present time?
- When & where did you last work?
- Were you having trouble with your job?
- How long did you work there?
- Why did you stop working?
- Why didn't you return to work?
- What is your disability?
- How does your disability interfere with your ability to work?
  - Symptoms?
  - How frequent?
- How were you able to get to this hearing?
- Can you predict when you are going to have a panic attack?
- Are you getting treatment?
  - With whom?
  - What kind of treatment? Therapy and medications?
- How long have you had treatment?
  - Does it help?
- Describe a good day?
  - Bad day?
- Do you know when you're going to have a bad day?
- How many good days would you say you have in a month?
  - How many bad days?
- Would you be able to work if you got a job with very little stress that required simple tasks and had only one or two other people there?
  - Why not?
- What do you have for income?
- Do you take care of your household? What do you do? Need help? Why?
- Do you go shopping? How often? Need help? Why?
- How is it you could go shopping but not be able to get a job?
- Do you manage your money? Do you need help?
- Are there things you used to enjoy doing but can't anymore because of your disability?

## How long does the hearing last?

Usually about 20-30 minutes.

## When will I get a decision?

The judge will try to make a decision within 30-90 days.

## What if I don't agree with the Administrative Law Judge's decision?

Decisions issued by the Administrative Law Judge in Vermont are reviewed by the Decision Review Board. You do not have the right to appeal an Administrative Law Judge's decision to the Decision Review Board. The cover letter attached to the decision sent to you by the Administrative Law Judge will inform you whether your case has been selected for review by the Decision Review Board. If selected, the Decision Review Board has 90 days, plus five days for mailing, from the date of your decision to complete its review.

If the decision in your case is selected, the Decision Review Board will look over the records in your case to see if the judge's decision complies with the law.

If the Decision Review Board finds that the judge's decision does not comply with the law, it will send your case back for another hearing or it may issue a new decision. If it finds that the judge's decision complies with the law, it will send you a letter to let you know. It will also tell you that if you disagree with the action it took, you may file a civil suit in Federal court.

Consult the yellow pages of your local phone directory for lawyers who specialize in this type of case, or contact the Vermont Lawyer Referral Service at 1-800-585-8852. If you cannot find a competent private attorney, you may contact the South Royalton Legal Clinic at (802) 763-7718, or VT Protection & Advocacy at 1-800-834-7890.

## If I win my case, when will my benefits start?

Once you're found eligible, there is no waiting period for SSI benefits.

You must be disabled for 5 full calendar months before you can receive SSDI benefits for the first time.

### When will I get my check?

SSDI and SSI checks may be sent out at different times. It depends on your birth date.

<u>Birth date</u>	<u>Receive check</u>
1st – 10th	2nd Wednesday of the month
11th – 20th	3rd Wednesday of the month
21st – 31st	4th Wednesday of the month

For example: For all Social Security beneficiaries receiving benefits prior to May 1997 or receiving both Social Security benefits and SSI payments you will receive your check on the 3rd of the month

### How much will I get?

SSDI benefit amounts depend on how much you have worked in your life. SSDI is an insurance program you've paid into with your employment taxes.

The SSI benefit amount is currently \$674 (in 2009) per month for a single person living in his or her own home and \$1,011 per month for an eligible couple living in their own home.

#### JAY'S STORY, Part II:

To maintain his SSDI benefits, Jay has to be diligent about not working too much. Jay is only allowed to earn about \$800.00 per month from employment without jeopardizing his SSDI money. He is fortunate to have a Case Manager/Service Coordinator from CAP who helps him to monitor his hours to ensure that he does not go over his monthly cap and who also helps him send in his pay stubs to the Social Security Administration for verification purposes.

In times when he has been out of work, for example due to injury or in Jay's case, during CAP's reorganization period which resulted in limited employment resources for about a year, he has also received minimal SSI benefits to help with daily living expenses.



## NOW THAT I'M GETTING BENEFITS — what do I have to do to keep them?

### Will I get to keep my benefits for the rest of my life?

Social Security will review your case every 1-3 years, and at the end of a 9 month trial work period, unless your ticket to work is active. (See Ticket to Work section.) The review is done to see if you are still disabled. This is called a Continuing Disability Review (CDR).

### Are there things I must tell Social Security?

Anyone who receives SSI or SSDI is required to report certain changes to the Social Security Administration. Some of those changes include:

- a change of address
- a change in living arrangement (someone moves in with you or a friend or relative helps you pay your living expenses)
- a change in income (you get a job, win the lottery, get an inheritance)
- a change in resources (you inherit a house or land),
- you become eligible for other benefits
- a change in marital status
- you enter or are discharged from a hospital, public institution, private institution, prison
- a change in school attendance, if you are under age 22
- you leave the United States temporarily or permanently
- change in citizenship or immigration status
- improvement in your medical condition
- a warrant has been issued or is outstanding for your arrest
- any change in your Ticket to Work status
- any change in work or Plans to Achieve Self-Support expenses

If you are receiving SSI all of these events may affect your check and/or your Medicaid eligibility. If you are collecting SSDI some of these changes may affect your eligibility and health care coverage.



- These changes must be reported immediately.
- It's OK to call Social Security to report changes, but it is best to write SSA a letter. Be sure to keep a copy of this letter for your file. Also, keep a copy of any documents that prove any of the changes in your status (from above list).

## CYNTHIA'S STORY, Part I:

I agonized over the decision to resign from my job and apply for Social Security Disability. Psychologically, retiring at this young age (30) left me feeling like a burden on my young family and unproductive in society as a whole. I now had to face the fact that I would never be able to net a salary that reflected my full earnings potential. Ten years have passed, and this is still one of the issues that plays heavily on my psyche.

I had heard horror stories from people who had tried unsuccessfully many times to get on SSDI. However, for me the decision to admit that I had become handicapped, and needed to apply for benefits, was much harder than actually getting approved for the program. I was accepted for SSDI on the first try, and began receiving my benefits within six months.

I feel that my success in getting into the SSDI program was due in part to the fact that I completed all forms with great care. I noted specific problems that I incurred due to the handicap that were not listed on the forms. I also wrote a letter explaining my history, past, present and family; and current problems in great detail.

I followed all instructions completely, asked questions when I didn't understand the meaning of a question, even if it meant waiting hours on the phone to speak with a Social Security representative or going in person to the Social Security office. I was also aggressive in having the doctor's offices follow through. The doctors as well as the treating hospitals sent all my medical records. I obtained a copy of all these documents for my own records, as well.

# 5. Overpayments

## What is a “Notice of Overpayment”?

A scary letter from Social Security which says you got too much money and they want you to pay it back...in 30 days!

DON'T PANIC!!! and  
DON'T THROW THIS LETTER AWAY!!!

## How did this happen?

Usually overpayments occur if:

- You don't report a change to Social Security such as all wages from work.
- You report a change and Social Security doesn't “get it,” and they keep sending you a check.

You may not realize you're receiving benefits that you're not entitled to. This is why it's so important to keep good records—so you can document what information you've provided to Social Security if problems come up. Always keep a copy of the changes you report to SSA. Ask for a receipt letter to be sent to you.

## WHAT IF...

**I've started working full time, reported my earnings to Social Security, and know my checks should have stopped... but they haven't. WHAT SHOULD I DO?**

- Notify Social security in writing
- Make a copy of the check and return it to SSA, return receipt requested, or in person and get a receipt proving that you returned it. We suggest this because if you put more than \$2,000 into the savings account that may effect you eligibility for SSI or Medicaid benefits.

## I don't have the money to pay it back. WHAT ARE MY OPTIONS?

- Ask for RECONSIDERATION. This means you want SSA to look at your case again, either by looking at your file or by meeting with you in a conference. Ask for a reconsideration if you think the amount of the overpayment is wrong, or the reason SSA gives for the overpayment is wrong.
- Ask for a WAIVER. If you agree that you were overpaid, you can still ask SSA to waive it so that you don't have to pay it back. Ask for a waiver if you think that the overpayment was not your fault and you can't afford to pay the money back.
- Ask for a PAYMENT ARRANGEMENT. Do this if you think that the overpayment was your fault or you can afford to pay it back. You can tell SSA that you want to pay the money back a little at a time.



**Whatever you decide to do, act promptly!  
Do not just put the notice aside.  
If you ignore the notice, SSA will start taking  
money out of your future checks!**

## I was not overpaid the amount they say. WHAT ARE THE RULES FOR REQUESTING A RECONSIDERATION?

- Make your request for RECONSIDERATION in writing to the Social Security office.
- File your request within 60 days of getting "Notice of Overpayment" letter.
- Ask for one of the following types of review:
  1. CASE REVIEW. An SSA worker will review the papers in your file and make a new decision based on this file review.
  2. INFORMAL CONFERENCE. You meet with the person who will decide your case to go over your file, to give new information, and to tell your side of the story.
  3. FORMAL CONFERENCE. You can bring witnesses to help present your case to the SSA worker.

## **I had my reconsideration and Social Security still says I was over paid. NOW WHAT?**

You can request a hearing before the Administrative Law Judge. Contact Social Security to request form HA-501, “Request for Hearing by Administrative Law Judge.”

## **I was overpaid, but it wasn't my fault and I can't afford to repay it. HOW DO I ASK FOR A WAIVER?**

Call the Social Security office and ask for form ask for form SSA-632 Request For Waiver Of Overpayment Recovery Or Change In Repayment Rate.

This form asks you questions about whether you reported the change and whether you knew you should report the change. It will also ask questions about your income. Remember, you must show both that the overpayment was not your fault and that you do not have enough money to pay back the overpayment.

Some reasons that may show that the overpayment was not your fault are:

- You have trouble reading.
- You did not know what you had to report to SSA.
- You have trouble remembering or understanding directions.
- You believed you reported every change that might have caused an overpayment.
- You were not told the reporting requirement.
- You were in the hospital in crisis and couldn't report the change.
- You did report to SSA, but they lost the report.



### **VERY IMPORTANT**

- If Social Security has told you your checks are going to be stopped, tell them you want to keep getting benefits until the appeals process has run its course.
- You only have 10 days from the time you receive a notice to tell them to keep the checks coming.

## **AUTOMATIC WAIVERS FOR SMALL OVERPAYMENTS**

SSA must automatically waive your overpayment if:

- the amount is less than \$1000  
and
- you did not cause the overpayment by making a false statement to SSA,  
and
- you request a waiver or a reconsideration.

### **Can I appeal if my waiver is denied?**

YES. The appeals process is the same as in the previous chapter, under “determining eligibility.”

### **I’ve lost all my appeals. Do I have to pay the money back?**

YES. But if you do not want your entire SSDI benefit check withheld monthly until the overpayment is recovered, you can request partial benefit withholding each month such as \$50 or \$100. If you don’t request that, your entire SSDI benefit check will be withheld. Most SSI overpayments are recovered at the rate of 10% of the SSI payment amount until the overpayment is resolved.

### **What if I need help appealing my overpayment?**

Contact Vermont Protection and Advocacy at 1-800-834-7890

## 6. Work Incentives

For many years, if you worked even part time, you could lose all your disability benefits. Now, the Social Security Administration (SSA) offers many work incentives for people who receive disability benefits. This section explains some of the terms that you'll hear about as you think about returning to work.

Not all the incentives are listed in this manual. For more information, contact your local SSA office or visit their website at [www.socialsecurity.gov](http://www.socialsecurity.gov) or contact Benefits Counselors at the Vermont Center for Independent Living at 1-800-639-1522 or 229-0501.

**If you get Social Security Disability Insurance (SSDI), here are some key things for you to know:**

- **SUBSTANTIAL GAINFUL ACTIVITY (SGA)** refers to how much money you can earn before losing your SSDI. As of January 2009, the SGA rate was \$980 per month (\$1,640 per month if you are blind). SGA goes up each year.
- **TRIAL WORK PERIOD (TWP)** is a period of 9 months where you can test your ability to work and earn money, and still get your full SSDI check. The nine months don't have to be all in a row, but they do have to fall within a 60-month (5 year) period. To use a trial work month all you have to earn is \$700.00 a month in 2009.
- **EXTENDED PERIOD OF ELIGIBILITY (EPE)** is the 36-month period that starts after you have completed your Trial Work Period. During this time, if your checks have stopped because you are working, but your income falls below SGA, your checks can start again, without a new application or disability determination.
- **IMPAIRMENT-RELATED WORK EXPENSES (IRWEs)** are costs of certain items or services that you need in order to work. These costs can be deducted from your earnings when figuring out if you are making SGA. Examples of IRWEs are costs of attendant care, special transportation or vehicle modifications, durable medical equipment like wheelchairs, or home modifications like ramps or railings.

- **EXPEDITED REINSTATEMENT (EXR):** During the 5 years after the EPE, if your benefits have stopped because you are working, you can ask for your benefits to start again without having to file a new application if you stopped working because of your disability. You can get up to 6 months of checks while SSA determines if you are eligible again. This will depend on if your job ended due to a worsening of your disability that caused you to no longer be able to work and earn above \$980.00 per month.
- **SUBSIDIES** are deductions available to individuals who are working with extra supervision, a job coach, or extra help in training by the employer. The employer will receive a form from SSA if you request the subsidy be taken into account. If SSA agrees that you are receiving a subsidy, your total counted income will be reduced by the amount of the subsidy.
- **CONTINUING DISABILITY REVIEWS (CDRs)** are reviews that SSA does periodically to update your medical files and determine if you are still disabled. Two important notes about CDRs: first, if you have received SSDI benefits for at least 24 months, returning to work alone will not trigger a CDR. Second, if you are taking part in the Ticket to Work program by assigning your ticket, described later in this booklet, SSA may not do CDRs on you if you have assigned your Ticket to Work. A work-related CDR will be generated at the end of your 9-month trial work period.

**6.****If you get Supplemental Security Income (SSI), here are some key things for you to know:**

- **SSI INCOME DISREGARDS:** For every \$2 you earn, your SSI check only goes down \$1.
- **STUDENT EARNED INCOME EXCLUSION:** If you are under age 22 and are not married or a head of household, some of your earned income is not counted if you are regularly attending school. In 2009, up to \$6,600 could be excluded. This amount goes up every year.
- **PLAN TO ACHIEVE SELF-SUPPORT (PASS):** It is an SSI provision to help individuals with disabilities return to work. SSA lets you save income or resources in a special account for certain work goals, such as saving for school or vocational training that could help the individual return to work.
- SSI eligibility and payment amount are based on income and resources (things of value that individual owns).



- PASS lets disabled individual set aside money and/or things he or she owns to pay for items or services needed to achieve a specific work goal.

## **THE TICKET TO WORK AND WORK INCENTIVES IMPROVEMENT ACT OF 1999**

VP&A

49

THE TICKET TO WORK AND WORK INCENTIVES IMPROVEMENT ACT (TWWIIA) was signed into law by President Clinton in December 1999. The purpose of the law is to help people who receive SSDI and SSI return to work and move off cash benefits.

### **What is the Ticket to Work Program?**

The Ticket to Work Program was created by the TWWIIA law in 1999. It offers more choices for getting vocational and employment services for people with disabilities who want to work.

### **Who gets a Ticket?**

All eligible beneficiaries can receive a Ticket. Tickets are mailed to newly disabled beneficiaries in the next cycle which usually takes place within 30-60 days after they are on the roles and picked up in the DCF.

Participation in the Ticket to Work program is voluntary. You do not have to take part in the program to keep your disability benefits.

### **What do I do with my Ticket?**

You can use your Ticket to get vocational and employment services from any participating Employment Network (EN). ENs are private companies or government agencies that have agreed to work with SSA to provide services at no cost to beneficiaries with disabilities.

The Ticket to Work program is currently managed by a company called MAXIMUS. They can provide more information about the program and provide names, addresses and telephone numbers for ENs that serve Vermonters.

6.

## PARTICIPANT B'S STORY

[Participant] is a 49-year-old woman, born and raised in Vermont, who has been diagnosed with Clinical Depression and Post-Traumatic Stress Disorder. She says she has “suffered for as long as I can remember” and that it wasn’t until 8 years ago when she walked into the office of Rutland Mental Health, burst into tears and said that she needed some help, that she could actually put a name to what she had been struggling with all of her life. With the help of what she calls her “extended family” at Rutland Mental Health, she has learned that what she was told for so many years as a child—that she was stupid and a misfit—wasn’t true and that the abuse she had suffered was not her fault.

It wasn’t until the end of her 14-year marriage that she became gainfully employed. She started doing cleaning jobs and with high praise and word of mouth, she soon had two employees working for her. “That’s how I supported my children” said [Participant], until she found herself hospitalized in intensive care due to a heart condition. Her physical health difficulties exasperated her mental health difficulties and she reports having “to start all over again.”

She had no health insurance, and went into huge debt due to her medical bills. She had applied for SSDI but was denied numerous times because the Social Security Administration made the determination that she was “able to work.” [Participant] stated that she didn’t attempt to appeal the SSA’s decision because at the time she was “too proud” to rely upon such financial supports, however, looking back on it she says “I should have pursued it to get me back on my feet.”

Although [Participant] stills suffers bouts of depression and episodes related to the trauma she has experienced throughout life, she says it’s easier to acknowledge and deal with the effects of her past because of all the help she has. She says that without the support she’s received from Rutland Mental Health, “there’s no doubt I’d be dead.” Just like what her grandmother once told her, [Participant’s] advice to others in similar situations is this: “It’s okay—there are so many people out there available to help.”

**For more information about the Ticket to Work Program, call MAXIMUS at 1-866-968-7842 (1-866-833-2967 TTY) or visit their website at [www.yourtickettowork.org](http://www.yourtickettowork.org).**

### **What happens when I go to an EN?**

If you decide to participate in the Ticket to Work program, the EN you choose will work with you to develop a plan for employment. The plan will include your goals for the kind of work you want to do, and will list services the EN will provide to help you reach your goals. When you have agreed on your goals and service needs, your counselor will write up your Individualized Plan for Employment (IPE) and have you sign it. At the same time, your counselor will ask you to assign your Ticket to Work to the EN. Assigning your Ticket allows the EN to be paid by SSA for the services they provided to you.

**VP&A**

**51**

### **Why should I take part in the Ticket to Work Program?**

In addition to getting services to help you go to work, when you are using your Ticket, SSA will not do Continuing Disability Reviews (CDRs) on you. This CDR protection will last for at least the first 2 years after you assign your Ticket. It can continue longer if you meet certain work requirements.

### **Do I have to work full-time?**

No! You can work part-time. You decide what's best for you.

**6.**

**I'm thinking about returning to work but am afraid I will make too much money and lose all my benefits.**

**Can somebody help me make an informed decision?**

Benefit Planning Outreach and Assistance Counselors will examine the impact of earned income on all your benefits, and advise you about your options.

### **Where Can I find a Benefit Planning Counselor?**

(see chart on next page)

Benefit Planning Counselors		
<u>Organization</u>	<u>Geographical Area</u>	<u>Phone</u>
Vermont Center for Independent Living (VCIL)	State-wide	1-800-639-1522 or 802-229-0501
VT Division of Vocational Rehabilitation	Barre / Montpelier	(802) 476-1619
	Bennington	(802) 447-6472
	Brattleboro / Springfield	(802) 257-2879
	Burlington	(802) 951-1230
	Middlebury	(802) 388-4666
	Morrisville	(802) 888-0662
	Newport	(802) 334-4337
	Rutland	(802) 786-5925
	St. Albans	(802) 524-4797
	St. Johnsbury	(802) 748-6685
White River Junction / Bradford	(802) 281-5033	

**“I wished I had a benefit specialist to work with me. Although I had knowledge of the system, it was difficult emotionally to deal with everything. I believe Benefit Specialists are one of the best resources out there, although they are very underused.”**

**– Gary**

# 7. Medicaid and Medicare

## MEDICAID

VP&A

53

### What is Medicaid?

It's a form of Health Insurance.

### What does it cover?

Doctor visits, prescriptions, hospital stays, emergency room visits, tests & x-rays, mental health services, substance abuse treatment, home health care, occupational therapy, physical therapy, speech therapy, and in some limited cases, dental and eye care.

### Who is eligible?

- People with disabilities who have low income and limited resources.
- SSI recipients.

There are other Medicaid programs for non-disabled people, but this resource book will focus only on programs for folks with disabilities.

### Can I work and still receive Medicaid?

YES! In many cases, a program called Medicaid for Working People With Disabilities (WPWD) allows you to work, earn more money and still be eligible for Medicaid benefits.

See the chart on following page:

7.

### MEDICAID FOR WORKING PEOPLE WITH DISABILITIES \*

<u># of People Living in Home</u>	<u>How Much You Can Earn per Month</u>
1	\$ 2,178
2	\$ 2,928
3	\$ 3,678
4	\$ 4,428
5	\$ 5,178
6	\$ 5,928

\* (as of January 2008, these amounts are updated annually by the State of VT)

In addition you may not have more than \$5,000.00 in assets or resources per individual, with exclusions such as your home or car. You may not have more than \$6,000 per couple.

### Can I receive Medicaid if I get SSI?

If you get SSI, you will automatically get Medicaid.

## 7.

### I get SSDI only. Do I still qualify for Medicaid?

MAYBE. Only if your SSDI check is small enough and you are under the asset limits and resource limits. See note in box above.

### I have a disability but don't get SSI or SSDI. I really need health insurance. Can I still be eligible for Medicaid?

ABSOLUTELY! You have to prove the same things to show you are disabled just as you do when you apply for SSI or SSDI (see chapter 4).

You must also meet the income and assets test.

## How do I apply for Medicaid?

Call the Vermont Health Access Unit at 1-800-250-8427, or go to a local Department of Children and Families office and tell them you want to apply for Medicaid.

## How long will it take for them to make a decision?

Usually a decision is made within 30 days.

## What can I do if I'm denied?

Call the Health Access Unit and ask for a Fair Hearing. The phone number is 1-800-250-8427.

You can also call the Vermont Healthcare Ombudsman at 1-800-917-7787.

### CYNTHIA'S STORY, Part II:

Some people are handicapped from the beginning of their life, others progress into a handicapped life, while yet others are abruptly thrown into becoming handicapped. Each of these situations is very stressful and each person and their family members must come to terms with their conditions.

The mental health needs of disabled persons are often overlooked but should be a part of each person's overall care. Learning to cope with financial and physical changes; learning how to explain illnesses and communicating newly acquired needs; dealing with stresses such as retiring at early ages, facing death, and expressing fears of becoming a burden are but a few of the examples of mental health issues that a handicapped person is forced to deal with.

All physicians and health care professionals should be alerted to the mental health needs of the handicapped, and direct their patients to seek counseling from the beginning of their situation.

# MEDICARE

## What Is Medicare?

A federal health insurance program. It has four parts: A, B, C & D.

## VP&A

56

## What services does it cover?

PART A covers hospital stays and skilled nursing facility care (nursing homes).

PART B covers doctor's office visits.

PART C is like an HMO. Medicare Advantage plans are available in many areas. People with Part A and Part B can choose to receive all of their health care services through one of these provider organizations under Part C

PART D covers outpatient prescription medication. Medicare part D coverage may also be included in Medicare Advantage Plans in some areas.

## Who is eligible to receive Medicare?

Any SSDI beneficiary.

## I've been found eligible for SSDI. When do my Medicare benefits begin?

Coverage begins 24 months from the time you were entitled to receive SSDI.

## Do I have to pay anything?

PART A is free to SSDI beneficiaries.

PART B costs \$96.40 a month plus any surcharges minus any Medicare Advantage reduction, plus any IRMAA.

PART D: See following page Medicare Part D.

7.



## Can I have Medicaid AND Medicare coverage at the same time?

YES, if you meet the income and assets test for Medicaid and are disabled.

## Are there any Prescription Drug benefits with Medicare?

Medicare Part D is available to everyone with Medicare coverage, regardless of income and resources, health status, or current prescription expenses.

You may sign up for Medicare Part D when you first become eligible for Medicare. If you don't sign up when you are first eligible, you may have to pay a penalty when you do sign up.

The cost of your prescription drug coverage under this program will depend on the kind of health care coverage you now have. You can join the Medicare Prescription Drug Plan or the Medicare Advantage Plan or other Medicare Health Plans that offer drug coverage. The Benefits Planning Outreach Assistants at the Vermont Center for Independent Living can help you to understand which program would be best for you. To make an appointment with them you should call 802-229-0501 or call toll free at 1-800-639-1522.

Medicare Prescription Drug Coverage Plans work like regular insurance plans. They may have a monthly premium, which varies by plan, and may have yearly deductibles. You may also have to pay part of the cost of prescriptions. If you have Medicare and Medicaid or Vscript or Vscript Expanded or Medicaid for Working People with Disabilities or a limited income, you may qualify for Medicare Part D at little or no cost to you out of pocket.

## Can I get help paying for the Medicare Prescription Drug benefit?

People with limited income and assets can get Extra Help with Medicare prescription drug plan costs. To get this help, you will need to file an application for Extra Help with the Social Security Administration. You can file over the Internet at <https://secure.ssa.gov/apps6z/i1020/main.html> or by calling 1-800-SSA-1213 to request a form.

To qualify you must:

- Have Medicare Part A, Part B or both;
- Live in one of the 50 States or the District of Columbia;
- In 2009 have resources of \$12,510 or less (\$25,010 if you are married)

- and live with your spouse), not counting your home or your car; and
- Have annual income for 2009 less than \$16,245 for an individual or \$21,855 for a married couple living together. Even if annual income is higher, you still may be able to get some help if you support other family members who live with you, have earnings from work, or live in Alaska or Hawaii. The income limit for Alaska is \$20,295 for an individual or \$27,315 for a married couple living together. The income limit for Hawaii is \$18,690 for an individual or \$25,140 for a married couple living together.

## 58

### **Can I keep my Medicare coverage if I go to work?**

YES. You get to keep 93 consecutive months of hospital insurance under Medicare if you return to work and earn more than \$980 per month (in 2009).

### **I'm not happy with a decision about my Medicare. Who can I call?**

You can call the Center for Medicare Services at 1-800-633-4227 or TTY 1-877-486-2048

# 8. PABSS- Protection and Advocacy for Beneficiaries of Social Security

VP&A

## What Is PABSS?

59

PABSS provides information, referrals, legal, and advocacy services to beneficiaries of Social Security Benefits in overcoming barriers to employment

## What Can This Program Do For Me?

PABSS can help you:

- Understand your rights and how to assert them;
- Obtain supports to help you succeed in your job;
- Keep you Social Security and health benefits;
- Address any concerns about the Social Security "Ticket to Work" incentives program;
- Investigate and pursue claims of disability discrimination in areas such as employment, education, and housing if the discrimination is a barrier to work;
- Address overpayment of benefits caused by work activity.

## Who Is Eligible for PABSS services?

8.

To be eligible an individual must: be a resident of Vermont and a recipient of Social Security disability benefits, including SSDI, SSI, and continuing Medicaid/Medicare benefits.

## How can I contact PABSS?

Contact: Vermont Protection and Advocacy at 1-800-834-7890 or (802) 229-2603 (TTY)

# 9. State of Vermont Independent Living Services

## VOCATIONAL REHABILITATION (VocRehab)

VP&A

60

### What Is VocRehab?

VocRehab assists Vermonters with disabilities to find and maintain meaningful employment in their communities. Basic vocational rehabilitation services include counseling and guidance, job assessments, education, occupational training coursework, books, tools, sign language interpreter services, adaptive equipment or prosthetics and job placement, etc. VocRehab is an employment network (EN) in the Social Security Ticket to Work Program discussed in Chapter 5.

### Who Is Eligible for VocRehab Services?

To be eligible for Vocational Rehabilitation services in the state of Vermont, an individual must:

- Must be a State resident.
- Have a disability that is a substantial barrier to employment. Disabilities may include physical limitations, mental illness, learning disabilities as well as other disorders.
- Require the assistance of Vocational Rehabilitation to become or remain employed.

### How Do I Apply?

Contact VocRehab at 1-866-VR-WORKS (Voice/TTY). 12 district offices are located throughout Vermont in Barre, Burlington, Rutland, Springfield, Bennington, Brattleboro, Middlebury, Morrisville, Newport, St. Albans, St. Johnsbury and White River Junction. More information is available at the Voc Rehab website: <http://vocrehab.vermont.gov>

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## Vermont Division for the Blind and Visually Impaired

The Division for the Blind and Visually Impaired provides vocational rehabilitation services for blind and visually impaired individuals. Contact the Division for the Blind and Visually Impaired at (802) 241-2210 for more information on eligibility and services.

## Deaf and Hard of Hearing Services

Deaf and Hard of Hearing Services is a service offered by the Department of Disabilities, Aging and Independent Living. Deaf and Hard of Hearing Services (DHHS) serves individuals with hearing loss to ensure equal access to the services of all departments, divisions and programs within the Agency of Human Services (AHS), such as VocRehab. This service provides information/referrals and system advocacy. Contact 802-878-5209 (Voice), 802-241-3557 (TTY) for more information.

VP&A

61

# State of Vermont Independent Living Services

## THE ATTENDANT SERVICES PROGRAM

VP&A

62

### What Is The Attendant Services Program?

A consumer-directed, personal assistance program that helps Vermonters with disabilities live more independently.

### What Can This Program Do For Me?

It can pay an attendant to provide you with physical assistance to help with certain activities of daily living. Some examples include:

- Bathing
- Dressing
- Positioning
- Eating
- Preparing meals
- Shopping
- Care of Adaptive Equipment

### Who Is Eligible for the Attendant Services Program?

To be eligible an individual must:

- be a Vermont resident,
- be at least 18 years old, and
- meet all of the eligibility criteria for one of the following programs:

#### I. GENERAL FUND PERSONAL SERVICES

- have a disability;
- need physical assistance with at least one activity of daily living or meal preparation; and
- be eligible to receive Medicaid.

9.

2. GENERAL FUND PDAC - Participant Directed Attendant Care

- have a permanent & severe disability;
- need physical assistance with at least two activities of daily living; and
- be able to direct your own personal care services.

3. MEDICAID PDAC - Participant Directed Attendant Care

- have a permanent & severe disability;
- need physical assistance with at least two activities of daily living;
- be able to direct your own personal care services;
- be willing to hire an attendant other than a spouse or civil union partner; and
- be eligible to receive Medicaid.

VP&A

63

**How Do I Apply?**

Contact: Attendant Services Program

Voice: (802) 241-2431

TTY: (802) 241-3557

# State of Vermont Independent Living Services

## REACH UP

VP&A

64

### What is REACH UP?

A program to help Vermont families with children make a better life for themselves by assisting the parent in going to work.

### What can they offer me?

- Money to help pay living expenses
- Medicaid health insurance
- Childcare costs
- Transportation costs
- Money for school or training
- Work-related costs such as clothing, tools, supplies
- Preparation for work
- A case manager to help you identify goals and create a plan to be successful

### Who is eligible for this program?

To be eligible for this program, you must:

- have one or more children
- meet the income and assets guideline
- be able to participate in your plan (i.e. work or go to school)

### How can I find out more about this program?

Contact: Department of Children & Families at 1-800-287-0589

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**“I was at a crossroads...live or die! (I was) a single mother with two children, a debilitating psychiatric disability, and not enough money to survive on my SSI check.**

**Reach Up helped me climb out of the grave I was digging for myself. With a lot of support, I returned to school as the first step in creating the life I wanted. Today I hold a master’s degree and am professionally employed. I enjoy life and really like myself.”**

**– E.M., Burlington**

**VP&A**

**65**

### **NANCY’S STORY:**

Nancy is a 47 year old, single mother of two adolescent girls. She holds a Bachelor’s degree in Early Childhood Education and a Bachelor’s degree in Nursing. 13 years ago she had an accident. She was pretty badly burned. She got infections that didn’t heal. She ended up having both legs amputated below the knees.

“For 22 years I have run my own in-home pre-school business in Burlington which is certified by the state. At one time I had 50 kids enrolled. Now there are about 32. The kids in my preschool have always been OK (with my disability) but the parents at first seemed apprehensive...many wondered if I could still work with and protect their kids while they were at my preschool.”

Nancy was experienced in childcare and enjoys what she is doing. She seems very comfortable in this atmosphere and mentioned several times how comfortable the children are with her and her disability.

**9.**

# State of Vermont Independent Living Services

## CHOICES FOR CARE

VP&A

66

### What is Choices for Care?

Choices for Care is a Medicaid-funded, long-term care program to pay for care and support for older Vermonters and people with physical disabilities. The program assists people with everyday activities at home, in an enhanced residential care setting, or in a nursing facility.

### What can this program do for me?

Support includes hands-on assistance with eating, bathing, toilet use, dressing, and transferring from bed to chair; assistance with tasks such as meal preparation, household chores, and medication management and increasing or maintaining independence. A second program is for Moderate Needs individuals who need minimal assistance to remain at home. This program offers limited case management, adult day services, and/or homemaker service.

### Who is eligible for this program?

To be eligible for Choices for Care a person must:

- Be a Vermont resident.
- Be 65 years of age or older or 18 years of age or older with a physical disability.
- Meet specific clinical criteria.
- Meet financial criteria for Vermont Long-Term Care Medicaid.

### How do I apply?

Choices for Care Program Applications and Information are available at Area Agencies on Aging and your local Home Health Agency. Call the Division of Disability and Aging Services at (802) 241-2648 for more information.

VP&A

67

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# 10. Personal Stories

VP&A

ELIZABETH ANN

68

ElizabethAnnWilson, born and raised in Scotland, has Multiple Sclerosis (MS). She came to the United States when she was 21 years old and lived in California until 2001, when she moved to Montpelier, Vermont to be closer to one of her daughters. She and her cat live in a lovely Victorian home.

Her first symptoms of MS appeared at the age of 28. She experienced fatigue and difficulty with sitting or standing for too long. She was diagnosed with MS at that time, but didn't believe in the diagnosis because her symptoms went into remission for several years. When they re-appeared in the mid-nineties, with the loss of vision in her left eye and discomfort in the right side of her body, she continued to disbelieve she had MS. She began to walk with a limp and told people she had a skiing accident. Her friends, who knew better, confronted her and she slowly began to come to terms with the diagnosis. She admits how extremely difficult it was for her to accept her illness. For 25 years she was in denial.

Ann felt tremendous rage at the fact that she had MS. After all, she was a vibrant, strong and independent woman who didn't make it a habit to depend on people. She went through incredibly difficult inner work dealing with her fear, loss and finding the strength to continue.

She was working with a travel agency in California when her symptoms reared their ugly heads. Friends and co-workers provided tremendous support, but she was still feeling depressed by the change in her physical functioning. While receiving some disability benefits from Social Security, Ann continued to work successfully as a travel agent until September 11, 2001, when traveling came to a halt in this country.

When she moved to Montpelier, she was determined to become an active member of the community regardless of how depressed she felt. She volunteered at Studio Place Arts in Barre, VT, working with art exhibits that

10.

inspired her and helped her to feel connected. She worked with Vermont Center for Independent Living in their library that also helped her feel connected to the community. She continues her education and artistic interest in basket weaving and hopes one day to sell some of her work.

Proclaiming, “I have MS” were the words that helped Ann feel liberated. It was a real breakthrough and she started a support group for others struggling with MS. Although she was disillusioned by the process, and felt a bit helpless by the awareness that so many others also felt depressed, she continues to gain support from her friends and family, and continues to be an active member of society.

Ann doesn't turn to the Western Medical model for help with relieving her symptoms. She believes that taking drugs will make her worse in the long run. Without her physician's approval, she relies on alternative healing methods and has taken her health into her own hands. She works with one of her daughters who is an herbalist and takes certain herbal remedies that help to relieve the pain and discomfort that she often experiences. She also practices yoga and participates in a women's support group for emotional support.

When asked what words of wisdom she would like to share with others, Ann calmly and reflectively offered the following:

“Don't give up. Put yourself out there. Everybody has something to contribute. Find your interest...something that really moves you. Don't be put off by people who look at you with non-compassionate, confused and patronizing eyes. Being disabled doesn't mean you can't participate. Don't be afraid to ask for help”

Although she agrees that these words are difficult to live by all the time, every single day of the month, she still embraces them and strives to live life in a way that feeds her determination and to accept what is in the present moment.

## PERSONAL STORIES

### JAY

VP&A

70

Jay is a 35-year-old man with a great sense of humor, an extensive work history, and an overwhelming willingness to help others. His calendar is full with meetings for disability-related committees that he is a part of, educational events that he is asked to attend in order to demystify the notion of what it means to be disabled, and activities designed to promote the importance of self-advocacy. He is an avid outdoorsman, a father to a 6-year-old son with whom he visits regularly, and a friend to many. In addition, Jay is a man who lives his life with the information processing difficulties common amongst those who have suffered a traumatic brain injury.

Jay's world was turned upside down at the age of 6 when he was a passenger in a horrible car accident that killed the driver of the car—his mother. His ability to form lasting relationships and maintain a positive outlook on life have survived, despite having spent all of his youth and adolescent years being shuffled around family members' and foster homes. He speaks very fondly of those who have taken him in over the years, and especially of those in his current living situation. Although he pays room and board to an elderly gentleman in Castleton, he is a part of the family there. He also has a great network of supports through his involvement in Rutland Mental Health's Community Access Program (CAP), the Advocacy, Resources and Community (ARC), and the Green Mountain Self-Advocates.

Jay's employment history began prior to his high school graduation, through his involvement at the Smokey House Center—an alternative education setting in Danby, Vermont designed to teach at-risk students social, educational, and work skills while paying a minimal wage. Jay participated in sugaring activities and forestry while a student/employee at Smokey House, and spent his after-school time performing odd jobs around his neighborhood. Following high school, Jay utilized the services of CAP's employment support programs to find and maintain employment. He has held a variety of positions, most recently in the landscaping and construction fields. The work he has now is seasonal and he is once again working closely with the Career Choices Program at CAP to find a job of interest to him for the winter months.

Although Jay receives SSDI benefits, his reasons for working are twofold:

“For the extra money and because I get bored and depressed when I’m not working.” To maintain his SSDI benefits, he has to be diligent about not working too much, though. Jay is only allowed to earn about \$800.00 per month from employment without jeopardizing his SSDI money. He is fortunate to have a Case Manager/Service Coordinator from CAP who helps him to monitor his hours to ensure that he does not go over his monthly cap and who also helps him send in his pay stubs to the Social Security Administration for verification purposes. In times when he has been out of work, due to injury or during CAP’s reorganization period which resulted in limited employment resources for about a year, he has also received minimal SSI benefits to help with daily living expenses.

As for being a person who has a disability attempting to find or maintain employment, Jay says that he has not been discriminated against, partly because the CAP workers partner with employers who are willing to be involved in a supported employment program and partly because he doesn’t talk about his disability much on the job site. He says that one obstacle he has encountered is the process leading up to getting work—all the forms that need to be completed in the hiring process. Again, he says he is fortunate in that he usually has a CAP employment consultant join him on site to help with the paperwork.

The biggest obstacle to employment encountered, disabled or not, is the lack of available public transportation. Jay lives outside of Rutland City and finds it hard to coordinate rides to get him back and forth to work reliably. He relies upon friends and support persons, but doesn’t want to be a burden. He often ends up working out deals to pay for rides from co-workers, leaving him in a vicious cycle—earning money to pay for rides that enable him to earn money! But he doesn’t give up or give in as working provides a great sense of pride for Jay while also allowing him to save for the finer things in life—like his new all-terrain four-wheeler that he shows off pictures of with a smile from ear to ear.

Jay’s advice for those interested in becoming employed is this: “Disability shouldn’t stop you from what you want to do. Get into an employment program like CAP. Get involved—in programs, with advocates, and in the community.” Another look at his full calendar will demonstrate that Jay certainly lives by his own advice.

### Participant A

VP&A

72

[Participant] has a psychiatric disability. She was born in 1955 in Vermont. She lived with her sister in North Carolina during high school when there were racial riots erupting everywhere. She became political and wrote some passionate poetry about it. She had repressed her illness until her junior year, but then had a nervous breakdown. She received ECT, drug therapy, and “pushed everything down again.” She moved back to Vermont to her family, a family that had a lot of violence and sexual abuse in it, got involved with a married man, got pregnant and had two children. She began to get heavily involved in drugs and decided she couldn’t handle two children and gave the second one up for adoption.

In her twenties, she began to become aware of her own repressed memories of abuse that she suffered and worked extensively with a therapist. At 30, she was hospitalized again and applied for Disability Benefits. Her therapist went to bat for her and helped her receive benefits while she was healing and sorting through her life.

She had a fortunate turn of events while in her early 30’s. She was married to someone who loved her. It was positive, “a dream come true.” Although it didn’t last and she became suicidal after he left her, she recounts it to be the best thing that ever happened to her. She began to look at finding a career and what she wanted to do with her life. She pulled herself together, found a strength she hadn’t known before.

She stopped receiving disability benefits and went to technical school to become a dental assistant. She worked at her job for three years. It was challenging for her because the dentist she worked for seemed demanding and critical, bringing up a lot of old feelings for her. Although she had the best financial security she had had in her life, she found the work too demanding on her system and began to search for another career.

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She currently is a massage therapist in Vermont and she does psychic readings occasionally. She has an interest in what it takes to become a Medical Intuitive and has taken classes to satisfy her appetite for learning. She continues to get educated, but she feels she has a difficult time in seeing



things through and making them happen, especially if they're things she feel strongly about. She is hoping to find a mentor to help her with implementing her desires and pursuits more effectively.

When asked what she'd like to do if she could do anything, she said that if she could go back in time, she would go to school and be a mid-wife. She wished that she was more serious in her younger years. She is certainly serious now. She loves the arts and they have been her lifeline through her journey. She remembers her life the way it was and continues to have hope for the future. She is a photographer, and a lover and writer of poetry.

When asked what one thing could have helped her along in her journey she said, "a mentor, and friends who wouldn't let me make excuses for my life."

[Participant] has great strength in her voice, in the way she articulates her story, her ideas, her fears and hopes. She reminds us how much we all tend to focus on our weaknesses and forget how far we've come and only remember how far we've still got to go until we find what we're looking for, whatever that is. There seems as if there is always something wrong with us, whether we consciously feel it or not. She is able to honestly discuss her feelings of not being complete, being broken and not good enough, yet in the same breath sharing such immense completeness, presence, beauty, and hope in the words she chooses to describe her life at this time. She said she thought success was about taking risks, about making things happen, about passion, and loving what you do. She doesn't feel successful, but she's determined she will.

### Participant B

VP&A

74

“It’s okay to have a problem. It’s not a bad thing. There is help out there.” These are the words that [Participant] reminds herself, sometimes on a daily basis, in order to keep fighting away the despair, hopelessness, and traumatic memories experienced as a result of an abusive and neglectful upbringing. These are the words that [Participant]’s grandmother said to her when she was 16 years old, after she was kicked out of her parent’s house on the day of her 17-year-old brother’s funeral. These are the words that have propelled [Participant] into making a successful and rewarding life for her two daughters and for herself.

[Participant] is a 49-year-old woman, born and raised in Vermont, who has been diagnosed with Clinical Depression and Post-Traumatic Stress Disorder. She says she has “suffered for as long as I can remember” and that it wasn’t until 8 years ago when she walked into the office of Rutland Mental Health, burst into tears and said that she needed some help, that she could actually put a name to what she had been struggling with all of her life. With the help of what she calls her “extended family” at Rutland Mental Health, she has learned that what she was told for so many years as a child—that she was stupid and a misfit—wasn’t true and that the abuse she had suffered was not her fault.

In addition to regular counseling sessions and medication, [Participant] uses work as a type of therapy. “Work is a self-soother for me, it helps me feel good about myself.” [Participant] attempted to work while she was married, but her husband at the time was not supportive of her efforts. It wasn’t until the end of her 14-year marriage that she became gainfully employed. She started doing cleaning jobs and with high praise and word of mouth, she soon had two employees working for her. “That’s how I supported my children” said [Participant], until she found herself hospitalized in intensive care due to a heart condition. Her physical health difficulties exacerbated her mental health difficulties and she reports having “to start all over again.” She had no health insurance and went into huge financial debt due to her medical bills. She had applied for SSDI but was denied numerous times because the Social Security Administration made the determination that she was “able to work.” [Participant] stated that she didn’t attempt to appeal the SSA’s decision because at the time she was “too

proud” to rely upon such financial supports. However, looking back on it she says “I should have pursued it to get me back on my feet.”

Following improvements in her health [Participant] found work with a transit company, but believes she was discriminated against when they discovered her disability status. She said that she was treated differently and believes she was passed over for a full-time employment opportunity. “I had the impression that they didn’t want to offer health insurance to someone with my physical and mental health disabilities and that they didn’t want to deal with someone going to Rutland Mental Health.” She believed her employers were wondering if she “could really deal with” the pressures of full time employment given the fact that she was engaged in mental health treatment. Although she would have jumped at the opportunity to be employed full-time, when the job went to someone who did not have her seniority or skills, she decided she no longer wanted to work for a business that didn’t value her the same way as other individuals and made a smooth transition out of the job.

She then found herself in another dissatisfying employment situation. She worked for a small local orchard—baking, cleaning, and providing customer service in trade for housing and a small stipend. [Participant] said that she developed a strong emotional connection to the woman she worked for. After being taunted and teased by other employees for having no shame about her attendance at weekly counseling sessions and after living with “not fitting in —I was an outcast, I was different—I didn’t join in their after work drinking parties” [Participant] came to the realization with the help of her therapist that she was being taken advantage of by the business owner, whom she viewed as a kind, motherly figure. Unbeknownst to her at the time, the owner was actually preying on [Participant]’s dedication, eagerness to please, and the values of hard work instilled by her grandmother—traits she brought with her everyday to the job but that were not rewarded in any sense. She quickly left that job but remains concerned about the owner using the fact that she has a mental illness as a means to provide her with an unsatisfactory reference.

After going door to door for weeks seeking work, [Participant] has found much satisfaction in her current employment situations, both of which

## PERSONAL STORIES

VP&A

76

promote a sense of pride that she never thought possible earlier in life. [Participant] now works part-time out of her home as a subcontractor for the Vocational Rehabilitation Program providing telephone outreach to other disabled individuals who are going back into the workforce. She checks in with those newly employed to “see how it’s going” and then updates data information for their benefits counselors. [Participant] says it is “so rewarding meeting and talking to people I can relate to.” Although she would like to see this job provide more hours, the part-time job provides no health insurance, she does keep herself busy with a second job that stemmed from her love of painting. [Participant] had been renting an apartment from the Rutland County Community Land Trust that she refurbished with their permission. When her landlords saw the amazing work she had done to her own apartment, they asked her if she wanted to continue doing the same in other apartments that they owned, which she eagerly agreed to. [Participant] says that it really isn’t work to her, rather she finds it therapeutic, “I love to go into the worst and make it the best.”

Although [Participant] still suffers from bouts of depression and episodes related to the trauma she has experienced throughout life, she says it’s easier to acknowledge and deal with the effects of her past because of all the help she has. She says that without the support she’s received from Rutland Mental Health, “there’s no doubt I’d be dead.” Just like what her grandmother once told her, [Participant]’s advice to others in similar situations is this: “It’s okay—there are so many people out there available to help.”

## CYNTHIA

What day I became a handicapped person is really hard to say. I spent all my childhood knowing that I wasn't "normal". I was winded more easily than other kids. I didn't walk quite as fast as the others. I didn't choose to play games that involved running or stressful physical activities, especially in the hot weather. I felt that low energy made others secretly think that I was a lazy person.

I sought out medical attention at age 15 with a documented family history of a heart disorder called hypertrophic cardiomyopathy. The disease is an abnormal thickening of the heart wall and the heart is less resilient for pumping blood than a normal functioning heart. Doctors felt that I was not impaired enough by the disease to receive treatment. It was simply suggested that I pursue periodic check-ups, which I complied with.

I carried on a fairly normal existence; working, attending college, marrying, all while trying to make a doctor truly listen and believe that my heart did not function properly and that I would like further investigation of the problem to no avail. Each year rapid heartbeats, increased shortness of breath, and dizzy spells that scared me grew with greater frequency.

During the summer of my 30th year, I was scheduled for, and did undergo, an operation to untangle my bowels and remove an ovary. During the operation my heart had some trouble, including stopping for a brief period, and finally there was agreement that I did have heart related complications. At the time I was working full time as an accountant with a not-for-profit organization and still attending college part-time. By November I had been hospitalized several times and had had a pacemaker implanted. My illness was not improving and had taken over my life and I needed to stop working.

I agonized over the decision to resign from my job and apply for Social Security Disability. Psychologically, retiring at this young age left me feeling like a burden on my young family and unproductive in society as a whole. I now had to face the fact that I would never be able to net a salary that reflected my full earnings potential. Ten years have passed and this is still one of the issues that play heavily on my psyche.

## PERSONAL STORIES

VP&A

78

I feel that the ease I had getting into the SSDI program was due in part to the fact that I completed all forms with great care. I added specific problems that I experienced due to the handicap that were not listed on the forms. I also wrote a letter explaining my history, present circumstances, and family situation. I followed all instructions completely, asked questions when I didn't understand the meaning of a question, even if it meant waiting hours on the phone to speak with a Social Security representative or going in person to the Social Security office. I was also aggressive in having the doctors' offices follow through. The doctors, as well as the treating hospitals, sent all my medical records. I personally retrieved a copy of all these documents for my own records as well.

I have sought out groups in Vermont that deal with issues that most handicapped persons face in their daily lives. Representatives of these groups have been friendly and helpful each time I found one. I feel that it is imperative that every individual in Vermont, handicapped, non handicapped, employers, medical personal, elderly, and countless others should have access to each and every one of these useful groups

Some people are handicapped from the beginning of their life, others progress into a handicapped life and yet others are abruptly thrown into becoming handicapped. Mental health needs of the disabled persons are often overlooked, but should be a part of each person's overall care. Learning to cope with financial and physical changes; learning how to explain illnesses and communicating newly acquired needs; dealing with stresses such as retiring at early ages, facing death, and expressing fears of becoming a burden are but a few of the examples of mental health issues that a handicapped person is forced to deal with. All physicians and health care professionals should be alerted to the mental health needs of the handicapped and direct their patients to seek counseling right from the beginning of their new situation.

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If one is not born handicapped but becomes handicapped, that person must change the way they live, spend money, and plan for the future. These problems are largely overlooked by medical professionals, but certainly have a great impact on a newly handicapped person. Financial counseling that includes budgeting, planning for the future,

addressing medical needs for the newly handicapped person and their families, should be made available.

Equipment to aid the person with disabilities is important, but can be hard to obtain. In my own case I cannot walk far and at a minimal pace on an inclined slope before becoming very out of breath. I applied for an electric scooter using a prescription from a cardiologist and a noted pharmacy and was denied the equipment because I did not have a neurological disorder. At the present I use a cumbersome two wheel motorized scooter to get along. I made several payments on a credit card paying high interest to acquire a very necessary piece of equipment. And with this scooter being less than an ideal piece of equipment, I must plan each outing with great care; taking into consideration the accessibility of that trip.

Home employment opportunities often are the only choice for persons with handicaps to consider. If you are able to get around without too much physical restraint and enjoy selling, examples of home employment possibilities include selling Avon, Tupperware, or other products. The flexibility in hours is a great advantage here. Computer based businesses are another example of home based employment. I have found that retraining is one of the most common ways for both state and federal agencies to address reemploying persons that become handicapped.

You should learn as many possible pros as you can for hiring a handicapped person. Find out if tax incentives exist if hiring a handicap person and point this out at the interview. A positive attribute that I have used while interviewing is that I wished to work only a very few hours; while most people are looking for no less than 20 hours, I would be willing to work as few as 8 to 12 hours and not in just one day, but in two or three days should a job need tending to more than once a week.

One of the best places to get help in the job seeking business is from those in the job seeking profession, temporary employment agencies. These temporary agencies are located all over the state and they work hard to match the employer and employee. The draw back of using a temp agency is that a fee will be paid directly to them to pay their medical bills, not yours.

## PERSONAL STORIES

VP&A

80

I cannot close on this subject without a "hats off" to Middlebury College in Middlebury, Vermont. I worked there part time for an extended period of time and the faculty and staff at this great institution treated me with the utmost respect and courtesy. Never once was I questioned about the many times that I was ill and needed time off. Personnel offered on several occasion to aid in any special needs that I may have required. And the college facility and staff truly honored the meaning of equality to all of their employees. Even after months of missed time no one from the institute requested my resignation, they left me with my dignity, trusting me to make the decision.



## NANCY

Nancy is a 47 year old, single mother of two adolescent girls. She holds a Bachelor's degree in Early Childhood Education and a Bachelor's degree in Nursing. What follows is a deeply touching and reflective interview in which she relates her story.

VP&amp;A

81

**What did you dream you would do for work as an adult?**

I always said that I would be a nurse or work with kids. When I was a nurse I did pediatrics.

**What have you done for work in you life?**

I did babysitting, worked as a proofer in a bank, was a waitress, did nursing at North Country Hospital. For 22 years I have run my own in-home pre-school business in Burlington that is certified by the state. At one time I had 50 kids enrolled. Now there are about 32.

**What is your disability and when was the onset?**

About 13 years ago I had an accident. I had a foster child and spilled hot water while I was holding him. My main concern was to protect him. He was OK but my tennis shoes got soaked with the boiling water and so I was pretty badly burned. I got infections that didn't heal and so over a few year period, I ended up having both legs amputated below the knees.

**How does your disability affect your life?**

It slows me down. I'm not as confident in my job as I used to be, but I'm stubborn. Also I am still having other problems with healing after a hysterectomy I had a few years ago.

**How has your work been affected since your accident?**

There are days when there are pain issues and I can't work, but I have other staff (to run the center) and I can still be here with the kids but may not be able to be as involved physically.

10.

## PERSONAL STORIES

### **How do you cope with the specifics of your disability?**

VP&A

It just happens. I deal with it day to day. I'm stubborn. I push on. I fight for what I want and need.

82

I started a support group locally for other amputees and it's been very helpful for them. When I had my first amputation, I was told by the hospital that I had only one option for a vendor to use to get my prosthesis. There was no choice. I found that vendor to be rude and hard to work with, so I did some research and came up with 2 other prosthesis vendors in Vermont who serve the Newport area. Now new amputees are given the names of 3 prosthesis vendors by the local hospital. Now they have a choice.

### **What internal barriers impact your life?**

My confidence and my concern about what others are thinking about me. In the beginning I would worry about what other people would say about what I could or couldn't still do. The kids in my preschool have always been OK (with my disability) but the parents at first seemed apprehensive. Many wondered if I could still work with and protect their kids while they were at my preschool. I wondered if the parents who had their kids in my pre-school before my amputations would still want to bring their kids to me.

Also, I hate to admit this but until recently I didn't like speaking in public for the same reasons as above.

### **What external barriers impact your life?**

Other people's attitudes and assumptions about me, and physical barriers. I hate going out. I can do stairs to get into buildings but it's harder and I'm slower. Not many buildings around here have ramps. Ramps are so much better for me.

10.

### **Who are the people who have had a positive impact on your life since your disability?**

My own kids, Johanna and Jessica. They pushed me and encouraged me to

do as much as I could for myself. In the beginning I tried to depend on them too much and would ask them to do things for me that they knew I could do for myself. Initially I did not go to rehab and only had a little PT. My family (my mother especially) has always been very supportive. My mom wanted to do everything for me and in fact she often still tries to do too much for me.

Tony O'Connor has been a positive role model for me. My brother who is an immigration officer knew Tony and introduced him to me. Tony is a double amputee—he lost both his legs at age 15. Just this past week there was a piece on him on the local Burlington TV news talking about how active he is in recreation and sports despite his leg amputations.

### **Who has had a negative impact on your life since you became disabled?**

The public in general, especially older adults, the stares from strangers (adults) just about kill me. It bugs me and it bugs both my daughters also. In an airport recently a child started to ask their mom “What happened to that lady?” I would have been happy to tell them, but the mom scolded her child for asking and moved her away from me. Also, sometimes people treat me as if they think that I am mentally incompetent just because I am in a wheelchair.

I'll tell you another thing that bugs me is the rudeness of people when I am in my wheelchair. Some don't acknowledge that I am even there, and others are irritated because I take up too much room or are in their way, and still others have tried to move along with me since they think that I will get special treatment because I am in a wheelchair (like not having to wait in line).

### **What lessons have you learned or what would you do differently?**

I probably would have tried to do things sooner that I thought I couldn't do—like speaking in public. Recently I was very disturbed about an issue in our community and I went to a public hearing and stood up and spoke my opinion. It wasn't as hard as I have been imagining.

## PERSONAL STORIES

VP&A

84

### **What thoughts or words of wisdom would you like to pass on to others with disabilities seeking employment?**

Start your own business. It helps to be able to have the flexibility that self-employment brings when I have bad days and can't work at my usual level.

**Don't give up!** If the first thing doesn't work, try something else.

### **In your own words, "what is success"?**

No gray hair. Getting my teens through high school. Living everyday proving to yourself that you can do anything you want to do. Just because you are disabled doesn't mean that you have to give up. You can still DO! Believe in yourself. Don't listen to the rest of the world.

Right after my amputations, a family member overheard my neighbor saying, "Look at her...How does she think that she can take care of kids?!" Well, here I am!

### **What are your hopes for the future?**

To continue with what I am doing.

### **Who or what impacted your situation while you were seeking employment?**

POSITIVE: I had my business established before my disability occurred. My parents were a lot of help after I was back. VR also helps by paying for my stump sox and they are very expensive. And most of the families of the kids I take care of wanted me back in business.

NEGATIVE: The work incentives. I run a business and pay my employees but I don't pay myself. I can't risk losing my Medicare. My medical costs are too expensive. Right now I work for peanuts and hugs!

### **Do you have any other comments you would like to share on the topic of disability and employment?**

I think they should make it easier to maintain your medical benefits for life without also having to give up a living wage.

Also some of the Medicare rules don't make sense to me. I am a nurse and can take care of my own dressings, so I do not need a Visiting Nurse Agency nurse to come into my home to take care of my dressings. However, Medicare denies coverage for my dressing supplies because I won't accept VNA Registered Nurse services. It just doesn't make sense.

VP&A

85

## PERSONAL STORIES

### SHERI

VP&A

86

Sheri was born two months premature. She experiences poor vision because she has a lazy left eye. She also has hydrocephalus, processing disorder, epilepsy and varying levels of depression. Sometimes she has troubles with balance, hand-eye coordination and depth perception. She knew from an early age that her life would present challenges. Most adults in her life, except for her parents, had limited expectations of her and Sheri developed limited expectations of herself as well. Sheri's childhood dream was to become a special education teacher and join the army.

School was always difficult for Sheri mostly because of her learning disability. Some teachers ignored her disabilities, and Sheri felt that she was "pushed" through school too quickly. Sheri was in Special Ed class for a year and a half, and during that time she learned that "these kids get pushed through the cracks" and she felt that during this experience "she found her calling."

After high school Sheri could not join the army because of her disabilities. She volunteered with the Marshall Center, and then worked there full time during the summer. The Marshall Center wanted to hire her permanently but couldn't because of financial limitations. The next summer Sheri worked in the housekeeping department at a local hospital. This job was hard for Sheri because her poor vision made it difficult for her to see where she had used the cleaning chemicals. Sheri's next job was at Twin Crafts Soap Factory; she was the first person with a disability to be knowingly employed by the company. Her first job in the factory worked well, in part because she didn't need to have strong hand-eye coordination. Sheri was moved to a new location in the factory and was even made supervisor of one of the lines.

While working at the factory Sheri earned her Associates Degree in Human Services. She also completed an internship at Perkins School of the Blind. Sheri is only thirteen credits away from a Bachelor's Degree in Education.

10.

Most recently, Sheri was working at the City Clerk's Office in St. Albans. This job started well for Sheri because she had a strong support group and an individual who contacted health care providers and agencies who work with Sheri to understand her strengths as well as her restrictions. The job was flexible and perfectly designed for Sheri. Unfortunately, she no longer works there and misses her job and friends.

Sheri is not working now, but she would like to again soon. She would rather work than receive social security. “I don’t want to be a burden to my family I don’t want to be a burden on society.” Sheri would really like to return to her former job, but if this isn’t possible she will look for other employment.

Sheri is no stranger to facing barriers to employment. Sheri has to walk everywhere she goes, take a taxi, or depend on a friend for a ride because she cannot drive. She also feels that other people’s lack of support and limited expectations have hurt her, because people don’t think she can do things or work. She says that she has baffled doctors and her family because she has managed to work and go to school. She said that once someone gets a “label” of being “sick” or “slow” it sticks, and people won’t let you try.

If Sheri was going to do something differently she would make her employers more aware of how her disabilities might affect her job performance and discuss clearly options and arrangements to support her success. She has learned not to take “no” for an answer until she has “exhausted every other possibility.” Sheri says that if a job is something that is really worthwhile to you it will “mean everything to you” and you should fight for it. Sheri has a strong support system now, but she wishes that she had one earlier.

Sheri emphasizes the importance of a support system for someone with a disability who would like to work. Sheri has learned who she can really count on for help; she tries to solve things on her own, but if she can’t she will work with the person who could help her most.

Sheri says, “The biggest problem is that employers are not educated that people with disabilities CAN do things.” It’s hard for anyone to get a job today; most jobs require a college degree. When you don’t have a degree, and you have a disability as well, it will take you that much longer to find work. Sheri says that you should tell people “Yes I have this limitation, but I can still do things well.” She says that you should try to let people know what you can do well and ask if there is something that you can do that uses your skills. Sheri said that sometimes even if you don’t follow your dream, you may find a job that makes you just as happy.

## PERSONAL STORIES

### GARY

VP&A

88

A knee operation made Gary unsuccessful in returning to his work. Gary went on workman's compensation benefits shortly after the birth of his daughter in June of 1989. A purchase of property in Vermont allowed Gary and his wife to move to Vermont. Here they thought they could make the money from the workers compensation stretch further. Gary went through several months of physical therapy. During this time of recovery, Gary happened on a life-changing event.

#### COLLEGE AND WORK

In 1990, Gary stopped by the Morrisville Community College of Vermont (CCV). His intention was to pick up a catalog for his wife who was interested in taking classes. The woman at the desk engaged him in conversation. "She really engaged me." He made an appointment to see a counselor and signed up full time for classes. "It was a life changing experience. It just changed my whole life." Gary went on to complete an Associates Degree in Liberal Arts at CCV. While attending CCV Gary enjoyed working as a Guardian Ad Litem for the Family Courts. He enjoyed volunteer work and community and human services. Gary started working as a support worker for a mental health agency while at CCV.

After CCV, Gary went on to Johnson State College and obtained a Bachelors degree in General Studies. He also started a Masters in Counseling program at Johnson. While at Johnson State Gary enjoyed psychology and law. He studied under various attorneys while "reading for the law" for several months. During this time Gary began working as Therapeutic Case Manager for the mental health agency working with children and families. Gary saw his role as a helper and advocate for teens and young adults with disabilities. He ultimately became adept at providing transitional services, and very good at "crisis work." His marriage ended in 1996 and at first he seemed to cope quite well.

10.

#### DEPRESSION

In 1992 Gary's primary physician noticed symptoms of depression in Gary and referred him to services. Gary seemed to manage the symptoms even though they got worse over time. During the summer of 2001 Gary says he



“burned out—I guess it needed to happen-, it was another life-changing experience.” He had taken several weeks off for depression. Gary requested reasonable accommodations at work. However, the reasonable accommodations proved unhelpful and in his doctor’s estimation would not be helpful and would exacerbate his condition.

Gary went back to work towards the end of the summer, started getting “really overloaded.” He says his employer was not as understanding as you would expect them to be, especially because they were a mental health agency. It was as if they were unaware. Although once they “became aware they were as helpful as they could be.”

### HOSPITALIZATION

After a severe emotional crash, Gary checked into Dartmouth for ten-day stay, and got out the day after 9/11/01. His experience in the hospital led him to write *A View from the Other Side*, which was published as an article in *Counterpoint*. “I developed a different understanding and respect to clients. I had always been the helper, but empathy is not the same as being able to relate because you’ve been there.”

He had filed for short-term disability (lasts six months) while at work. “Then it became clear I wasn’t going to go back to work.” He was diagnosed with severe and chronic depression and anxiety disorders. Looking back Gary reflects that as early as 1988 he had symptoms of Seasonal Affective Disorder and depression. He had been depressed for approximately two years, but had been able to manage.

### SYMPTOMS

Prior to his hospitalization, Gary noticed symptoms getting worse. They were: forgetting appointments; not able to focus; very forgetful; not wanting to go out of his apartment; and perceiving situations out of proportion. He says, “A letter from a bill collector would devastate me; everything was out of perspective — even the simplest things.”

Gary reflects that he used to love his job, but instead of looking forward to working, he began to reschedule appointments not wanting to go to work.

## PERSONAL STORIES

“It was so overwhelming, it was hard to cope.” Everything, even the simplest tasks, were difficult. “I had money but didn’t even want to pay the bills.”

VP&A

FALL 2001

90

Gary lived in an apartment his employer owned. Part of his job was managing the building and supporting the residents. Since he was no longer working, his employer asked him to move out so someone else could take over. His short-term disability payment was half of his income and he soon used up his savings. A friend offered to let him and his two daughters stay in her home. They stayed there for a couple of months and then house-sat for another friend for a couple of months. While Gary was on short-term disability he filed for long-term disability through the Social Security Administration.

There came a time when his short-term disability ended and he had not yet started receiving other benefits. His goal was just to get out of the house. He said his gym membership was integral to recovery. “I knew building a support system and having structure is one of the most important things for depression.” He had a relationship with his daughters and a couple of key friends. Although he had minimal support he made good use of them.

GOT SSDI

When Gary received his SSDI he said: “Such a burden was lifted—it really helped my recovery. I didn’t have to worry about having my needs met. My basic needs were taken care of.” Gary wished he had a benefit specialist to work with him. Although he had knowledge of the system, it was difficult emotionally to deal with everything. He says Benefit Specialists are one of the best recourses out there, although they are very underused. Gary feels that without SSDI, he would have “probably crashed due to having been forced to go back to work. I could have easily gone back into the hospital, something I did not want.”

SUMMER 2002

The Summer of 2002 was “phenomenal”, according to Gary. He got off of medications, did a 100-mile bike ride and became a certified spinning instruc-

tor. In the fall of 2002, he went to massage school in Barre, which was small and close enough to home that he didn't need to request any accommodations. The instructor took a holistic approach and was very supportive.

He also went for help from VR. Gary had great experiences with Vocational Rehabilitation Services while working as a case manager, but now “when I told them (VR) I was applying for SSDI they said, ‘No one gets it the first time.’” Initially they said they would assist with tuition fees “until they knew I was going to start a business and work for myself, and then they said I needed a business plan.” He says he didn't get any “positive feedback” from VR. In his view they had “no understanding of emotional disability.” The information needed to complete a business plan was “very overwhelming.” He was “just trying to meet [his] day to day needs. VR wasn't helpful. In fact, they were detrimental and I wasn't in a place to say this really isn't helpful.” Gary felt that VR didn't understand what the money represents to someone with an emotional disability; it represents a tangible means of support. In the same way that a letter from the bill collector can be overwhelming and send you into the pit of despair, the same effect—except magnified ten times—happens when you get a letter from VR saying they'll contribute only \$100.00 towards tuition. The money is a tool.”

Gary ended up receiving help through Central Vermont Community Action and finished the business plan, although he never received any financial help from VR. Gary did receive some funding from VSAC for tuition in massage school. “Although it was only a month and a half of tuition, it was helpful”. He completed course work at Vermont School of Professional Massage. He is slowly working on starting a massage practice.

Gary continues his education in several areas. He continues to attend massage trainings, and is interested in equine massage. Gary has started workshops in “couples massage”. Gary also has almost completed his training as a Reike Master/Teacher and will begin teaching Reike in early 2004. In October of 2003, Gary started a Masters of Science program in Sport Psychology through CAPELLA University. The online format allows Gary to work within his comfort level. Gary also is on the state Roster as a non-licensed and non-certified psychotherapist.

## PERSONAL STORIES

### WRAP-UP

VP&A

92

Gary's personal goal is to get a master's degree— "I want the degree and the knowledge that comes with it, but I also need (and want) the structure that comes with it." He has some massage clients and does volunteer work; recently taking a class on massaging people with disabilities. He is "forging a new professional identity. I still have the helper mentality and have to check my boundaries constantly and take care of myself."

## GAYLE

When asked to write about my experience of living with a disability, it seemed like a fairly simple request. And it will be hard to explain why I find that it surely isn't, but I will make the attempt. To begin, this is asking far too much introspection on my part—never my strong suit.

Prior to January 20, 1995, I think it is safe to say I had a fairly standard and very good life. I lived in South Royalton with my husband of 15 years, and we both worked at our jewelry business in town. We also balanced that intensive indoor work with leading hiking trips for a Bristol company, and alternated our time away from the shop. We were both active with our local rescue squad, and Bill was a firefighter as well.

We had decided to shift the focus of our business back to creating only Cloisonné pieces for galleries and our work had been accepted at a gallery in Hawaii and one in New York. Bill had built me a beautiful new studio on our land, and we were looking forward to a more peaceful lifestyle. It was this point that life chose to reshuffle the deck.

In a heartbeat the entire world I had known changed. We were traveling together to Arizona, to learn the hiking trails there, as well as attend a gem show. A boy coming home from college fell asleep at the wheel and hit our vehicle. It is hard to put into words the horror of all that followed that one moment in time. Bill was killed instantly and I was thrown from the vehicle and critically injured. A helicopter came and took me to the nearest trauma center. Both our Dalmatian and I survived, though the injuries I suffered left me with both a physical and psychological disability.

My recovery from this day began with the loving support of our community and the very dear friends that were there for me. It would take far too many pages to tell the story of every kindness that pulled me through so dark a time! At every level, I was cared for through the months that followed. From coming home to a hospital bed set up in my living room to people coming by day and night through the following weeks to tend the fire and make sure I had food to eat, or just dear hearts to listen and hold me when I cried.

## PERSONAL STORIES

VP&A

94

I credit my friends with helping me to begin to seek out a new life for myself. It was their encouragement that fueled me day after difficult day. Vocational Rehabilitation was tremendously helpful, enabling me to job shadow when I found potential employment. I was absolutely adrift, no longer able to pursue the career I had been so good at and loved for over 20 years. I only knew I needed to find some work that could help me make sense of having been spared that day, something that ‘put back’ into a community that had given me so much. I held an assortment of jobs, six months here or there, doing anything that held an interest for me. I took a computer course, realizing that any job sought these days required those skills. I think, in retrospect, no one I knew would have allowed me to go on disability. I believe that we agree it was necessary for me to have work that would give some meaning to my survival, some way to express my gratitude for the gift of living.

One of the most key elements for my recovery has been the company of my “furkids”, primarily my assistance dog Basil. No other creature could provide the unconditional love and support provided by this handsome and terrifically smart canine. Times when it is physically difficult for me, he is there to provide strength and some physical support. He also helps to counter the daily struggle of Post Traumatic Stress Disorder. His affectionate and powerful presence steadies me through both physical and psychological difficulties.

There is some kind of amusing cosmic justice afloat, looking at my life these days. I know that prior to 1995 I held the standard prejudices about folks with psychiatric diagnoses, and yet I would have said I was above average in compassion. I think it is interesting that life chose to teach me a different viewpoint by gifting me with a challenge that would forever change that previous point of view. It seems more than coincidence that I now advocate for others with psychiatric diagnoses. The people I’ve met, who have told me their stories and shared with me their journeys, all give me the understanding that I’m doing what I was meant to do, and helping somewhat, through the insight I have been given.

# APPENDIX

## Guide to Resources 2009

VP&A

95

# I 3. Appendix

## GUIDE TO RESOURCES 2009

### VP&A Agency Resources

96

- ATTORNEY GENERAL'S OFFICE: (802) 828-3171  
CIVIL RIGHTS UNIT  
109 State Street  
Montpelier, Vermont 05609  
*employment discrimination*
- ATTENDANT SERVICES PROGRAM (802) 241-2431 (voice)  
*personal care services* (802) 241-3557 (TTY)
- CLIENT ASSISTANCE PROGRAM 1-800-769-7459  
Rutland  
57 North Main Street  
Rutland, Vermont 05701  
*Vocational Rehabilitation issues*
- CVOEO  
(Champlain Valley Office of Economic Opportunity)
- FAIR HOUSING PROJECT 1-800-287-7971 (voice/TTY)  
294 North Winooski Avenue,  
Burlington, Vermont 05401  
*housing discrimination*
- ENABLE LOAN PROGRAM  
(Vermont State Housing Authority) 1-800-820-5119 (voice)  
*funds for making your* 1-800-798-3118 (TTY)  
*home accessible* 1-802-828-3295



EQUAL EMPLOYMENT OPPORTUNITY COMMISSION <i>employment discrimination</i>	1-800-669-4000
HUMAN RIGHTS COMMISSION 135 State Street, Drawer 33 Montpelier, Vermont 05633-6301 <i>housing discrimination, state employment discrimination</i>	1-800-416-2010 (voice/TTY)
LAWYER REFERRAL SERVICES <i>legal referrals</i>	1-800-639-7036
MAXIMUS Ticket To Work, employment networks	1-866-968-7842 1-866-833-2967 (TTY)
REACH UP <i>money, support and planning for getting a job</i>	1-800-287-0589
SOCIAL SECURITY ADMINISTRATION Montpelier 33 School Street Montpelier, Vermont 05602 <i>disability benefits</i>	(802) 223-3476
SOCIAL SECURITY ADMINISTRATION Rutland Asa Bloomer Building 88 Merchants Row, Room 330, Rutland, Vermont 05701 <i>disability benefits</i>	(802) 775-0893 1-800-772-1213
SOCIAL SECURITY ADMINISTRATION Burlington 58 Peal Street Burlington, Vermont 05401 <i>disability benefits</i>	(802) 951-6753

SOUTH ROYALTON LEGAL CLINIC (802) 763-7718  
PO Box 117, Chelsea Street  
South Royalton, Vermont 05068  
*employment issues, disability benefits*

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98

VERMONT DEPARTMENT OF CHILDREN AND FAMILIES  
Economic Services Division (formerly PATH)  
*Medicaid application, reach up program,  
general assistance*

Barre	1-800-499-0113
Bennington	1-800-775-0527
Brattleboro	1-800-775-0515
Burlington	1-800-775-0506
Hartford	1-800-775-0507
Middlebury	1-800-244-2035
Morrisville	1-800-775-0525
Newport	1-800-775-0526
Rutland	1-800-775-0516
Springfield	1-800-589-5775
St. Albans	1-800-660-4513
St. Johnsbury	1-800-775-0514
Waterbury	1-800-287-0589

VERMONT CENTER  
FOR INDEPENDENT LIVING (VCIL) 1-800-639-1522 (voice/TTY)  
11 East State Street,  
Montpelier, Vermont 05602  
*benefits counseling,  
home accessibility program*

VERMONT LEGAL AID  
*employment &  
housing discrimination,  
disability benefits*

1-800-889-2047

DIVISION OF VOCATIONAL REHABILITATION

VP&A

99

Statewide  
*employment rehabilitation,  
benefits counseling*

1-866-VRWORKS (voice/TTY)  
(802)-241-1455 (TTY/next talk)

Barre-Montpelier  
McFarland State Office Bldg.  
5 Perry Street, Ste. 100  
Barre, Vermont 05641

(802) 479-4210 (voice/TTY)

Morrisville  
63 Professional Drive  
Morrisville, Vermont 05661-9724

(802) 888-5976 (voice)  
(802) 888-1329 (TTY)

Newport District Office  
100 Main Street, Suite 210  
Newport, Vermont 05855

(802) 334-6794 (voice/TTY)

St. Johnsbury District Office  
67 Eastern Avenue, Suite 3  
St. Johnsbury, Vermont 05819

(802) 748-8716 (voice)  
(802)748-6668 (TTY)  
1-888-868-8716

Burlington Regional Office  
108 Cherry Street, Suite 201  
Burlington, Vermont 05401

(802) 863-7500 (voice)  
(802) 652-6856 (TTY)  
1-888-654-2511

Middlebury  
282 Boardman Street  
The Community Service Building  
Middlebury, Vermont 05753

(802) 388-4666 (voice)  
(802) 388-4690 (TTY Next Talk)  
1-888-264-1498



St. Albans (802) 524-7950 (voice)  
State Office Building (802) 527-2166 (TTY Next Talk)  
20 Houghton Street, Room 105  
St. Albans, Vermont 05478

Rutland (802) 786-5866 (voice/TTY)  
190 Asa Bloomer Building 1-800-366-8611  
Rutland, Vermont 05701-9408

Bennington (802) 447-2780 (voice/TTY)  
200 Veterans Memorial Drive, Ste 15 1-800-742-6939  
Bennington, Vermont 05201-1998

Springfield (802) 885-2279 (voice/TTY)  
100 Mineral Street, Suite 308  
Springfield, Vermont 05156-2306

Brattleboro (802) 257-0579 (voice/TTY)  
28 Vernon St., Suite 400 1-800-451-4942  
Brattleboro, Vermont 05302

White River Junction (802) 295-8850 (voice/TTY)  
220 Holiday Drive, Suite A  
White River Junction, Vermont 05001-2015

VERMONT PROTECTION & ADVOCACY 1-800-834-7890

141 Main Street, Suite 7  
Montpelier, Vermont 05602  
*employment discrimination,  
Ticket To Work, overpayments  
abuse, neglect and civil rights violations.*

VABIR  
 VERMONT ASSOCIATION OF BUSINESS, INDUSTRY & REHABILITATION  
*employment rehabilitation*

	(802) 878-1107 state-wide
Bennington	(802) 447-2780
	(VABIR cont.)
Brattleboro	(802) 257-0579
Burlington	(802) 863-7500
Rutland	(802) 786-5866
White River Junction	(802) 295-8850
Middlebury	(802) 388-4669
Newport	(802) 334-4336
Springfield	(802) 885-8952
St. Albans	(802) 527-5441
St. Johnsbury	(802) 748-2771

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**101**

**Benefit Planning Counselors**

<u>Organization</u>	<u>Geographical Area</u>	<u>Phone</u>
Vermont Center for Independent Living (VCIL)	State-wide	1-800-639-1522 (voice/TTY)
VT Division of Vocational Rehabilitation	Barre/ Montpelier	(802) 476-1619
	Bennington	(802) 447-6472



Brattleboro/Springfield (802) 257-2879

Burlington (802) 951-1230

Middlebury (802) 388-4677

**VP&A** (VocRehab cont.)

**102**

Montpelier (802) 223-6355

Morrisville (802) 888-0662

Newport (802) 334-4337

Rutland (802) 786-5925

St. Albans (802) 524-4797

St. Johnsbury (802) 748-6685

White River Junction /  
Bradford (802) 281-5033

### **Designated Agencies**

(DD = Developmental Disabilities MH = Mental Health)

#### Addison County

Community Associates (CA) DD  
61 Court Street, Middlebury, VT 05753  
Phone: (802) 388-4021

Counseling Service of Addison County (CSAC) MH  
89 Main Street, Middlebury, VT 05753  
Phone: (802) 388-6751 (Voice/TTY)

#### Bennington County

United Counseling Services of Bennington County, Inc. (UCS) DD/MH  
1 Ledge Hill Drive, PO Box 588, Bennington, VT 05201  
Phone: (802) 442-5491 (voice/TTY)



## Chittenden County

Howard Community Services (HCS) DD  
102 South Winooski Avenue, Burlington, VT 05401-3832  
Phone: (802) 658-1914

Howard Center for Human Services (HCHS) MH  
208 Flynn Avenue Suite 3J, Burlington, VT 05401  
Phone: (802) 660-3678

VP&A

103

## Caledonia, Essex and Orleans County

Northeast Kingdom Human Services DD  
PO Box 724, 154 Duchess Street, Newport, VT 05855-0724  
Phone: (802) 334-6744

## Franklin, Grand Isle County

Northwestern Counseling and Support Services DD/MH  
107 Fisher Pond Road, St. Albans, VT 05478  
Phone: (802) 524-6555 (voice/TTY)

## Lamoille County

Lamoille County Mental Health Services, Inc. DD  
275 Brooklyn Street, Morrisville, VT 05661  
Phone: (802) 888-5026

Lamoille County Mental Health Services, Inc. MH  
520 Washington Highway, Morrisville, VT 05661  
Phone: (802) 888-4914

## Orange County

Upper Valley Services, Inc. DD  
267 Waits River Road, Bradford, VT 05033  
Phone: (802) 222-9235

Clara Martin Center MH  
11 Main St., P.O. Box G, Randolph, VT 05060-0167  
Phone: (802) 728-4466



## Rutland County

Community Access Program DD  
8 South Main St., PO Box 222, Rutland, VT 05701  
Phone: (802) 775-0828

Rutland Mental Health Services MH  
Phone: (802) 775-8224

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**104**

## Washington County

Community Developmental Services (CDS) DD  
50 Granview Drive, Barre, VT 05641  
Phone: (802) 479-2502

Washington County Mental Health Services, Inc. MH  
174 Hospital Loop, Berlin, P.O. Box 647, Montpelier, VT 05601-0647  
Phone: (802) 229-0591

## Windham and Windsor Counties

Health Care and Rehabilitation Services of Southeastern Vermont DD  
12 Church Street, Bellows Falls, VT 05101  
Phone: (802) 463-3962

Health Care and Rehabilitation Services of Southeastern Vermont MH  
1 Hospital Court, Suite 410, Bellows Falls, VT 05101  
Phone: (802) 463-3947



# NOTES

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105

# NOTES

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106