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## WORKING WELL WITH A DISABILITY INFORMED CONSENT FOR SURVEY I

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*Title:* Working Well With a Disability

*Sponsor:* National Institute on Disability and Rehabilitation Research

*Study Directors:* Catherine Ipsen, M.A.  
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*Special instructions to the potential participant:*

If this consent form is not clear to you, please contact Catherine or Nancy for an explanation.

*Purpose:*

The purpose of this research is to learn about the relationship between health conditions and long-term employment outcomes.

*Procedure:*

If you agree to take part in this research study you will answer questions about your health and employment experiences. You will be paid \$ for returning a completed survey to the researchers.

*Risks/Discomforts:*

You should experience no risks or discomfort as a result of answering the questions on this survey.

*Benefits:*

There is no promise that you will receive any benefit by answering the questions asked in this survey.

*Confidentiality:*

Your identity will be confidential. Your name will not be used when talking about or reporting the results of this project. Your signed consent form and returned surveys will be stored in a locked file cabinet and kept for two years after publication of the final report. Your survey answers will be stored on a researcher's computer for up to five years post publication of the final report. The data files will contain no identifying information.

*Permission to Contact You Again:*

When we receive your survey, we will keep your name, address, and phone number so we can contact you again in approximately one year for a follow-up survey. By signing this form, you are not agreeing to complete the second survey, you are giving us permission to contact you again in approximately one year.

*Compensation for Injury:*

Although we do not foresee any risk in taking part in this study, the following liability statement is required in all University of Montana consent forms.

"In the event that you are injured as a result of this research you should individually seek appropriate medical treatment. If the injury is caused by the negligence of the University of any of its employees, you may be entitled to reimbursement or compensation pursuant to the Comprehensive State Insurance Plan established by the Department of Administration under the authority of M.C.A., Title 2, Chapter 9. In the event of a claim for such injury, further information may be obtained from the University's Claims representative of University Legal Counsel. (Reviewed by University Legal Counsel, July 6, 1993)"

*Voluntary Participation/Withdrawal:*

Your decision to take part in this research study is entirely voluntary and you may withdraw from the study at any time.

*Questions:*

If you have any questions about the research now or during the study contact Catherine Ipsen at 406-243-4562, 888-268-2743, or by e-mail at [ipsen@ruralinstitute.umt.edu](mailto:ipsen@ruralinstitute.umt.edu) or Nancy Arnold at 406-243-2469, 888-268-2743, or by e-mail at [nancy@ruralinstitute.umt.edu](mailto:nancy@ruralinstitute.umt.edu).

*Participant's Statement of Consent:*

I have read the above description of this research study. I have been informed of the risks and benefits involved, and all my questions have been answered to my satisfaction. Furthermore, I have been assured that any future questions I have will be answered by a member of the research team. I voluntarily agree to take part in this study. I understand I will receive a copy of this consent form.

Printed or Typed Name: \_\_\_\_\_

Street Address or P.O.Box: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Phone: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Social Security Number (for reimbursement purposes): \_\_\_\_\_

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# **HEALTH SURVEY**

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**THE UNIVERSITY OF MONTANA  
RESEARCH AND TRAINING CENTER ON  
DISABILITY IN RURAL COMMUNITIES  
RM. 52, CORBIN HALL  
MISSOULA, MT 59808**

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## DEMOGRAPHIC INFORMATION

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Please fill in the following information about you. It provides the context for the rest of your answers on this survey.

1. Date of Birth: \_\_\_\_\_

2. Gender: (check one)

\_\_\_\_\_ Male  
\_\_\_\_\_ Female

3. County of Residence: \_\_\_\_\_

4. Do you live within the city limits?

\_\_\_\_\_ Yes    If yes:  
                  What city or town? \_\_\_\_\_

\_\_\_\_\_ No    If no:  
                  (a) How many miles to the closest city or town? \_\_\_\_\_

                  (b) What is the name of this closest city or town? \_\_\_\_\_

5. Education: (check one)

\_\_\_\_\_ Grades K - 8 (Elementary)  
\_\_\_\_\_ Grades 9 - 11 (Some High School)  
\_\_\_\_\_ Grades 12 or GED (High School Graduate)  
\_\_\_\_\_ College 1 year to 3 years (Some College or Technical School)  
\_\_\_\_\_ College 4 years or more (College Graduate)

6. Marital Status: (check one)

\_\_\_\_\_ Married  
\_\_\_\_\_ Divorced  
\_\_\_\_\_ Widowed  
\_\_\_\_\_ Separated  
\_\_\_\_\_ Never Married  
\_\_\_\_\_ A member of an Unmarried Couple

7. Which best describes you? (check one)

- Caucasian
- African American or Black
- Hispanic or Latino
- American Indian or Alaska Native
- Native Hawaiian of Other Pacific Islander
- Asian
- Other

8. Employment Status: (check one)

- Not Currently Employed
- Employed Full-Time
- Employed Part-Time
- Homemaker
- Student

9. Health Care Coverage:(check all that apply)

- Medicaid
- Medicare
- Military provided health insurance/benefits
- Indian Health Service
- Private Health Insurance/HMO
- No Health Insurance

10. Do you receive either of the following? (check all that apply)

- Social Security Income (SSI)
- Social Security Disability Insurance (SSDI)

11. Are you a recipient of a *Ticket to Work*?

- Yes
- No

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# HEALTH

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1. What is the **MAJOR IMPAIRMENT OR HEALTH PROBLEM** that limits your activities? (check only one)

- Arthritis / Rheumatism
- Traumatic Brain Injury
- Spinal Cord Injury (level of injury\_\_\_\_)
- Multiple Sclerosis
- Muscular Dystrophy
- Back or neck problem
- Cancer
- Amputee
- Fractures, bone/joint injury
- Hypertension / high blood pressure
- Walking problem
- Stroke
- Heart problem
- Lung / breathing problems
- Diabetes
- Hearing problems
- Cerebral Palsy
- Eye / vision problems
- Post Polio
- Other Impairment (Specify) \_\_\_\_\_

2. In general how would you rate your health? (check one)

- Excellent       Very Good       Good       Fair       Poor

3. Thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health **not good**? (circle one)

- 0   2   4   6   8   10   12   14   16   18   20   22   24   26   28   30

4. During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation? (circle one)

0 2 4 6 8 10 12 14 16 18 20 22 24 26 28 30

5. Thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health **not good**?(circle one)

0 2 4 6 8 10 12 14 16 18 20 22 24 26 28 30

6. Are you limited in any way or in any activities because of any impairment or health problem? (check one)

Yes  
 No

7. Do you now have any health problem that requires you to use special equipment, such as a cane, wheelchair, a special bed, or a special telephone.

Yes  
 No

8. Because of an impairment or health problem, do you need the help of other persons with your personal care needs such as eating, bathing, dressing, or getting around the house? (check one)

Yes  
 No

9. Because of an impairment or health problem, do you need the help of other persons in handling your routine needs, such as everyday household chores, doing necessary business, shopping, or getting around for other purposes? (circle one)

Yes  
 No

10. In general, how satisfied are you with your life? (check one)

Very Satisfied       Satisfied       Dissatisfied       Very Dissatisfied



## SECONDARY CONDITIONS

A secondary condition is a problem experienced after you already have a disability. For example, a person with back pain may develop arthritis. Arthritis would then be a secondary condition for that person. Like a health condition, a secondary condition may restrict your ability to do things independently.

Please rate how much each of the following conditions have affected your activity and independence in the last two months. If you have not experienced a secondary condition in the last two months, or if it is an insignificant problem for you, please circle "0". Please refer to the rating scale, which is reproduced on each page, in making your ratings.

- 0 = Not experienced during past two months/insignificant problem (rarely or never limits activity or independence)
- 1 = Mild or infrequent problem (limits activity 1 to 5 hours per week)
- 2 = Moderate/occasional problem (limits activity 6 to 10 hours per week)
- 3 = Significant/chronic problem (limits activity 11 or more hours per week)

**Examples:**                    **0 1 2 3**                    **Restlessness**    If you feel that restlessness limits your activities moderately (6 to 10 hours per week) you would circle a "2".

**0 1 2 3**                    **Dry Skin**            If you feel dry skin does not limit your activities circle "0".

<b>Secondary Condition</b>	<b>Description</b>
0 1 2 3 Pressure Sores	These develop as a skin rash or redness and may progress to an infected sore. Also called skin ulcers, bedsores, or decubitus ulcers. Persons who use wheelchairs are at risk for developing pressure sores.
0 1 2 3 Spasticity (Muscle Spasms)	Spasticity refers to uncontrolled, jerky muscle movements, such as uncontrolled muscle twitch or spasm. Often spasticity increases with infection. Persons with multiple sclerosis, cerebral palsy, and spinal cord injury are among individuals at risk for developing spasticity.

- |     |  |
|-----|--|
| 0 = | Not experienced during past two months/insignificant problem (rarely or never limits activity or independence) |
| 1 = | Mild or infrequent problem (limits activity 1 to 5 hours per week)   |
| 2 = | Moderate/occasional problem (limits activity 6 to 10 hours per week)   |
| 3 = | Significant/chronic problem (limits activity 11 or more hours per week)  |

## Secondary Condition

## Description

- |         |  |  |
|---------|--|--|
| 0 1 2 3 | Scoliosis<br>(Kyphosis/Lordosis)               | These three terms refer to an abnormal curvature of the spine. Scoliosis is the curvature of the spine sideways. Lordosis is the forward curvature of the upper back (hunchback). Persons with SCI are at risk of these because of not sitting right, muscle imbalance, or paralysis.  |
| 0 1 2 3 | Contractures                                   | A contracture is a limitation in range of motion caused by shortening of the soft tissue around a joint (e.g., elbow, hips). This occurs when a joint can not move frequently enough through its range of motion. Pain commonly accompanies this condition.  |
| 0 1 2 3 | Osteoporosis                                   | This is a wasting of bone. It may cause pain, can lead to fractures, and predisposes individuals to developing urinary tract stones. Any disabled individual who is not able to have adequate weight bearing exercise on their bones may develop osteoporosis, and women are at particular risk. It is diagnosed by a physician. |
| 0 1 2 3 | Arthritis                                      | Arthritis results from inflammation of the joints, making movement both difficult and painful. Symptoms include pain and swelling around the joints. Cold weather and stress can make this condition worse.  |
| 0 1 2 3 | Fatigue  | Fatigue is a tired (though not necessarily sleepy) feeling after minimal exertion.   |
| 0 1 2 3 | Physical Fitness /<br>Conditioning<br>Problems | Some disabled persons find they are not able to do as much as they would like because they are out of shape.   |

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- 3 = Significant/chronic problem (limits activity 11 or more hours per week)

<b>Secondary Condition</b>	<b>Description</b>
0 1 2 3 Eating or Weight Problems	This includes difficulty in regulating weight, as well as problems with eating (e.g., overeating, under eating, vomiting food).
0 1 2 3 Bladder Dysfunction	Incontinence, bladder or kidney stones, kidney problems, leakage, urine backup, and associated problems are all symptoms of bladder dysfunction. Persons with impaired or absent muscle function in the area of the bladder are at risk for bladder dysfunction.
0 1 2 3 Bowel Dysfunction	Diarrhea, constipation, "accidents," and associated problems are signs of bowel dysfunction. As with bladder dysfunction, persons with impaired muscle function or paralysis in the abdominal region are most likely to have bowel dysfunction.
0 1 2 3 Urinary Tract Infections	This includes such infections as cystitis and pseudomonas. Symptoms include pain on urination, a burning sensation throughout the body, blood in the urine, and cloudy urine. Persons with multiple sclerosis and spinal cord injury are especially at risk for urinary tract infections.
0 1 2 3 Sexual Dysfunction	This includes dissatisfaction with sexual functioning. Causes for dissatisfaction can be decreased sensation, changes in body image, difficulty in movement, concern over bladder and bowel routines.

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## Secondary Condition

## Description

- 0 1 2 3 Dysreflexia  
Dysreflexia (sometimes called hyperreflexia) results from interference in the body's temperature and blood pressure regulating systems. Symptoms of dysreflexia include sudden rises in blood pressure and sweating, skin blotches, goose bumps, pupil dilation and headache. It is often related to overflowing leg bags. Dysreflexia can also occur as the body's response to pain where an individual doesn't experience sensation.
- 0 1 2 3 Carpal Tunnel Syndrome  
This is a nerve disorder in the hand that causes pain and loss of feeling, especially in the thumb and first 3 fingers. Symptoms include numbness or tingling in part of the hand, shooting pains up the arm, thumb weakness, frequent dropping of objects, and shiny, dry skin on the hand.
- 0 1 2 3 Postural Hypotension  
This involves a strong sensation of lightheadedness following a change in position. It is caused by a sudden drop in blood pressure. Individuals with spinal cord injury or stroke may experience postural hypotension.
- 0 1 2 3 Cardiovascular (Heart) Problems  
This commonly involves high or low blood pressure and must be diagnosed by a physician because there are often no symptoms. Other heart problems may be signaled by fluid retention - usually resulting in swelling around the ankles.
- 0 1 2 3 Circulatory Problems  
Swelling of veins, feet, or the occurrence of blood clots.  
Specify: \_\_\_\_\_

- |     |  |
|-----|--|
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| 3 = | Significant/chronic problem (limits activity 11 or more hours per week)  |

<b>Secondary Condition</b>	<b>Description</b>
0 1 2 3 Respiratory Problems	Pneumonia and other respiratory tract infections can occur in disabled individuals. Symptoms of respiratory infections or problems include increased difficulty in breathing and increased secretions. Persons with quadriplegia, post polio, rheumatoid arthritis and multiple sclerosis are especially at risk for respiratory complications and infections.
0 1 2 3 Chronic Pain	This is usually experienced as chronic tingling, burning or dull aches. It may occur in an area that normally has little or no feeling.
0 1 2 3 Joint and Muscle Pain	This includes pain in specific muscle groups or joints. Individuals who must overuse a particular muscle group (e.g., persons with paraplegia who may strain shoulder muscles) or those who must put too much strain on joints are at risk of developing joint and muscle pain.
0 1 2 3 Depression	More than feeling blue. Symptoms include: extreme, long-term sadness, loss of pleasure in favorite things and activities, difficulty sleeping, weight loss or gain, thoughts of suicide and frequent and/or unexplained crying.
0 1 2 3 Anger	Extreme displeasure with situations or persons that is difficult to forget.
0 1 2 3 Isolation	Isolation from social contact and support may be a problem for some individuals, and may be due to a loss of relationships or being house-bound.
0 1 2 3 Problems with Mobility	Many physically disabled individuals are troubled by difficulty with getting around due to a loss of strength or muscle control.

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<b>Secondary Condition</b>	<b>Description</b>
0 1 2 3 Alcohol / Drug Abuse	This involves use of alcohol and/or drugs.
0 1 2 3 Diabetes	Diabetes is a problem resulting from irregularities in blood sugar levels. Symptoms include frequent urination and excessive thirst. This condition is diagnosed by a physician. Native American individuals and persons who are overweight are at higher risk for developing diabetes.
0 1 2 3 Anemia	Anemia is a low level of iron in the blood and often occurs in conjunction with pressure sores. Symptoms include fatigue and low energy. This condition is diagnosed by a physician.
0 1 2 3 Sleep Problems/ Disturbances	Difficulty falling asleep or staying asleep, difficulty staying awake during the day, or waking up early are all sleep disturbances.

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## CURRENT WAY OF LIFE & PERSONAL HABITS

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Please tell us how often you do each of the following.

Please answer each item as accurately as possible. Please do not leave any blank. (circle your answer)

N = Never

S = Sometimes

O = Often

R = Routinely

### How often do you...

- |     |   |   |   |   |   |
|-----|---|---|---|---|---|
| 1.  | Discuss your problems and concerns with people close to you   | N | S | O | R |
| 2.  | Choose a diet low in fat, saturated fat, and cholesterol  | N | S | O | R |
| 3.  | Report any unusual signs or symptoms to a physician or other health professional  | N | S | O | R |
| 4.  | Follow a planned exercise program   | N | S | O | R |
| 5.  | Get enough sleep  | N | S | O | R |
| 6.  | Feel you are growing and changing in positive ways  | N | S | O | R |
| 7.  | Praise other people easily for their achievements   | N | S | O | R |
| 8.  | Limit your use of sugars and food containing sugar (sweets)   | N | S | O | R |
| 9.  | Read or watch TV programs about improving health  | N | S | O | R |
| 10. | Exercise vigorously for 20 or more minutes at least three times a week (e.g., walk briskly bicycle, aerobic dance, use a stair climber) | N | S | O | R |
| 11. | Take some time for relaxation each day  | N | S | O | R |
| 12. | Believe that your life has purpose  | N | S | O | R |

N = Never  
 S = Sometimes  
 O = Often  
 R = Routinely

**How often do you...**

13.	Maintain meaningful and fulfilling relationships with others	N	S	O	R
14.	Eat 6 to 11 servings of bread, cereal, rice, and pasta each day	N	S	O	R
15.	Question health professionals in order to understand their instructions	N	S	O	R
16.	Take part in light to moderate physical activity (e.g., walking for 30 to 40 minutes five or more times a week)	N	S	O	R
17.	Accept those things which you cannot change	N	S	O	R
18.	Look forward to the future	N	S	O	R
19.	Spend time with close friends	N	S	O	R
20.	Eat 2 to 4 servings of fruit each day	N	S	O	R
21.	Get a second opinion when you question your health care provider's advice	N	S	O	R
22.	Take part in leisure time (recreational) physical activities (e.g., swim, dance, bicycle)	N	S	O	R
23.	Concentrate on pleasant thoughts at bedtime	N	S	O	R
24.	Feel content and at peace with yourself	N	S	O	R
25.	Find it easy to show concern, love, and warmth to others	N	S	O	R
26.	Eat 3 to 5 servings of vegetables each day	N	S	O	R
27.	Discuss your health concerns with health professionals	N	S	O	R
28.	Do stretching exercises at least 3 times per week	N	S	O	R
29.	Use specific methods to control your stress	N	S	O	R

N = Never  
 S = Sometimes  
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**How often do you...**

30.	Work toward long-term goals in your life	N	S	O	R
31.	Touch and are touched by people you care about	N	S	O	R
32.	Eat 2 to 3 servings of milk, yogurt, or cheese each day	N	S	O	R
33.	Inspect your body at least monthly for physical changes/danger signs	N	S	O	R
34.	Get exercise during usual daily activities (e.g., walk during lunch, use stairs instead of elevators, park your car away from your destination and walk)	N	S	O	R
35.	Balance time between work and play	N	S	O	R
36.	Find each day interesting and challenging	N	S	O	R
37.	Find ways to meet your needs for intimacy	N	S	O	R
38.	Eat only 2 to 3 servings from the meat, poultry, fish, dried beans, eggs, and nuts group each day	N	S	O	R
39.	Ask for information from health professionals about how to take good care of yourself	N	S	O	R
40.	Check your pulse rate when exercising	N	S	O	R
41.	Practice relaxation or medication for 15 to 20 minutes daily	N	S	O	R
42.	Are aware of what is important to you in life	N	S	O	R
43.	Get support from a network of caring people	N	S	O	R
44.	Read labels to identify nutrients, fats, and sodium content in packaged food	N	S	O	R

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**How often do you...**

45.	Attend educational programs on personal health care	N	S	O	R
46.	Reach your target heart rate when exercising	N	S	O	R
47.	Pace yourself to prevent tiredness	N	S	O	R
48.	Feel connected with some force greater than yourself	N	S	O	R
49.	Settle conflicts with others through discussion and compromise	N	S	O	R
50.	Eat breakfast	N	S	O	R
51.	Seek guidance or counseling when necessary	N	S	O	R
52.	Expose yourself to new experiences and challenges	N	S	O	R

**Thank you for your help on this survey.**