

6-2001

Health Status of Adult Montanans in Supported and Semi-Independent Living Arrangements

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Recommended Citation

Traci, Meg A. Ph.D.; Geurts, Sarah B.S.; Seekins, Tom Ph.D.; Burke, Rebecca M.S.; Humphries, Kathleen; Brennan, Lisa M.L.S.; and Rural Institute, University of Montana, "Health Status of Adult Montanans in Supported and Semi-Independent Living Arrangements" (2001). *Health and Wellness*. 28.

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RTC

RURAL

**Research and Training Center
on Rural Rehabilitation Services**



**Health Status of Adult
Montanans in Supported and
Semi-Independent
Living Arrangements**



The University of Montana
**RURAL
INSTITUTE**
*Center for Excellence in
Developmental Disabilities Education,
Research and Service*

Acknowledgments

This research is supported by grant #R04/CCR818162-03-1 from the **Office on Disability and Health**, Centers for Disease Control and Prevention, with additional support from the Montana Developmental Disabilities Planning and Advisory Council and the National Institute on Disability and Rehabilitation Research. Opinions expressed are those of the authors, and not necessarily those of the funding agencies.

The authors would like to acknowledge the following individuals and organizations. Without their contributions, this work would not have been possible.

RTC: Rural Researchers Craig Ravesloot, Ph.D. and Ann Szalda-Petree, Ph.D.

Other Project Staff: John Caruso, Ph.D.; Kathy Dwyer, B.S.; Linda Frey, M.A.; Bill Innes, M.A.; Catherine Ipsen, M.A.; John Jackson; Phil Matthias, M.D.; Bryan Ramirez; Sue Redmond; Steve Seninger, Ph.D.; and Diana Spas.

**Montana Developmental Disabilities Planning and Advisory Council:
Deborah Swingley and Greg Olsen**

**Montana Department of Public Health and Human Services:
Bob Moon, Joe Mathews, Maggie Bullock, and John Zeeck**

The Developmental Disabilities Health Promotion Project Advisory Panel

**Participants: Montana Community Developmental Disabilities Service Providers,
their Staff Members and the
Montanans with developmental disabilities whom they serve.**

Executive Summary

This study reports on the prevalence and severity of secondary conditions in adults with developmental disabilities living in 33 Montana counties. “Secondary conditions” are additional health problems acquired by an individual with a disability. Although the personal, social, and financial costs of these secondary conditions are extraordinarily high, they are frequently preventable. Ten of the top twelve secondary conditions reported by survey respondents involved issues that can be addressed by wellness activities or lifestyle management.

In particular, survey ratings of “Communication,” “Weight,” and “Physical Fitness” problems suggest that these areas may contribute to other problems. Efforts to improve communication skills, nutrition, and fitness might prevent, or reduce the severity, of many other reported secondary conditions. Data suggesting that more than half of respondents are overweight and that a quarter of these are obese are particularly disturbing. Worthy goals for this population would be to increase exercise and fitness, improve nutrition, and reduce the prevalence of obesity.

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June, 2001

The Health of Adult Montanans with Developmental Disabilities: Overall Summary of the Secondary Conditions Surveillance Report

This report summarizes data on the prevalence and severity of secondary conditions experienced by adult Montanans with developmental disabilities. In autumn of 1999, we surveyed 33 Montana counties, recruiting respondents from the mailing list of adults served by the Montana Department of Public Health and Human Services Developmental Disabilities Program (DPHHS-DDP).

A secondary condition occurs when an individual with a disability experiences additional complications that reduce independence. Secondary conditions may be expensive, and can significantly restrict activities and require extensive care. Proper precautions, including life-style management and self-care practices, may prevent secondary conditions. Secondary conditions may include:

Impairments – A contracture due to weak muscle tone in a person with cerebral palsy is an example of impairment that results in further loss of physical abilities.

Functional Handicaps – A functional handicap, such as communication difficulties, may stem from environmental obstacles the person encounters.

Additional Disabilities – A disability acquired after a primary disability (e.g., a spinal cord injury acquired by an individual with Down Syndrome).

Consumer-Driven Surveillance Procedures

We used the “Life Quality and Health for Adults with Developmental Disabilities: A Secondary Conditions, Risk and Protective Factors Surveillance Instrument” to gather the following information on the prevalence and severity of secondary conditions among Montanans. Respondents rated the severity of each secondary condition on a scale of 0 to 3, with “0” indicating the condition had not been a problem during the past year and “3” indicating that it had been a significant/chronic problem that limited activity 11 or more hours a week.

Surveys were sent to the 1,925 adults served by the Montana DPHHS-DDP. The survey return rate was 39% ($N = 749$). The

Project’s advisory panel designated direct care providers as the primary raters and consumers as auxiliary to the survey process. As a result, current data collection falls more clearly under the rubric of Constituency-Oriented Research and Dissemination (Fenton, Batavia, & Roody, 1993), which allows family members and service providers to act as representatives of the respondent.

Four measures were calculated for each secondary condition: the **percentage of respondents** endorsing an item, the **prevalence per 1000**, the **average severity rating** of that item, and a **problem index**. The percentage endorsing an item was calculated by totaling the number of

respondents who rated a secondary condition at 1, 2, or 3, divided by the total number of respondents to the item. Prevalence rate was calculated by dividing the number of persons endorsing an item by the total number of respondents, then multiplying by 1000. An average severity rating for each secondary condition was calculated by dividing the sum of severity ratings by the number endorsing the item. A problem index was calculated

by multiplying the percentage endorsing a secondary condition by the condition's average severity rating. This measure combines both frequency of occurrence and severity. Thus, the problem index ranks the most severe secondary conditions experienced by the most respondents. (See Table 2 for rankings of all the secondary conditions by problem index.)

Results

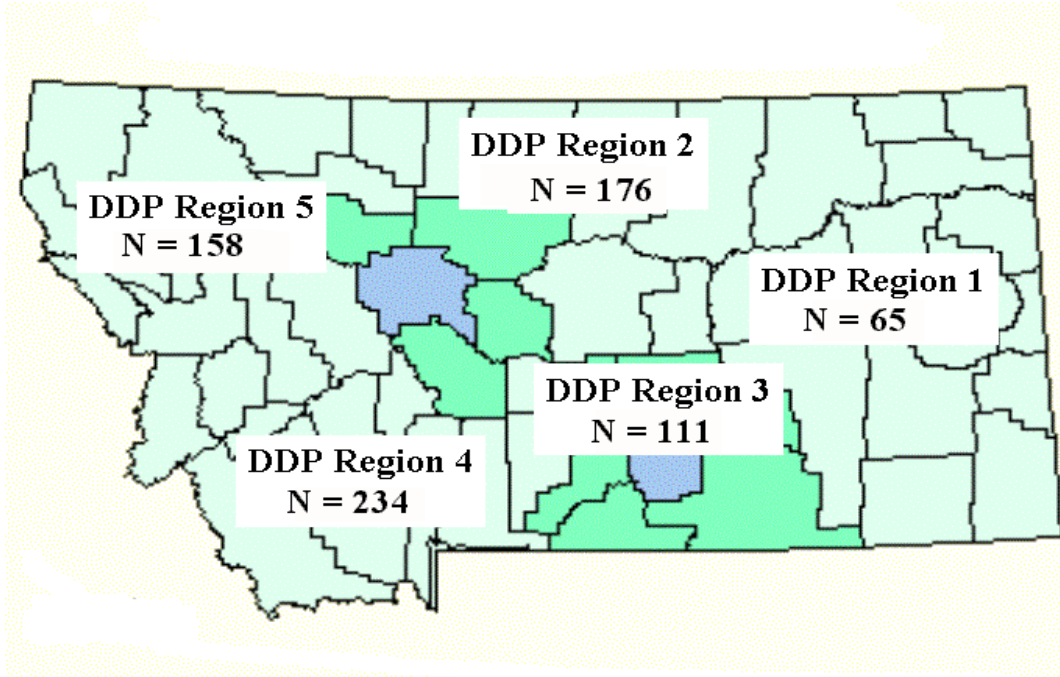
Seven hundred and forty-four* respondents resided in 34 Montana counties. Lewis and Clark County had the highest number of respondents (114 or 15%) followed by Yellowstone County (106 or 14%). Table 1 lists the number of respondents for each county.

Table 1: Number of Respondents per County (N = 749)

Beaverhead County	12	McCone County	3
Big Horn County	2	Meagher County	1
Blaine County	8	Missoula County	46
Cascade County	96	Musselshell County	1
Choteau County	20	Park County	1
Custer County	17	Phillips County	1
Dawson County	21	Pondera County	9
Fergus County	1	Powell County	11
Flathead County	40	Ravalli County	27
Gallatin County	2	Richland County	1
Granite County	2	Sanders County	20
Hill County	41	Sheridan County	20
Jefferson County	4	Silver Bow County	81
Lake County	22	Stillwater County	1
Lewis & Clark County	114	Teton County	2
Lincoln County	3	Valley County	2
Madison County	6	Yellowstone County	106

*Note: County of residence was not reported for five respondents (i.e., missing data for five cases).

Map 1: Distribution of Respondents across Montana Department of Health and Human Services Developmental Disabilities Program Regions



The U.S. Department of Agriculture assigns each U.S. county a “Beale Code” indicating the county’s degree of ruralness. Codes range from 0 (most-metropolitan) to 9 (completely rural). **Most respondents (69%) resided in remote-rural counties (i.e., non-metropolitan counties that are not adjacent to a nearby metropolitan county).** Only 4% resided in semi-rural counties (i.e., non-metropolitan counties that are *economically* adjacent to a metropolitan county, which implies that the non-metropolitan county residents commute to the nearby metropolitan county). The remaining 27% resided in urban counties (i.e., metropolitan counties with a population of at least 100,000).

There were more male (55%) than female respondents (45%). Respondents represented a wide range of ages, from 16 to 93, with a mean age of 44. Most respondents were white (91%). Six percent were Native

American and fewer than 1% were Black, Asian, White and Indian, or Hawaiian. Two percent of the respondents reported their ethnicity as Latino.

Ninety-three percent of respondents endorsed mental retardation (MR) as their primary disability, with the remaining participants endorsing either cerebral palsy, Down Syndrome, fetal alcohol syndrome, autism, epilepsy/seizure disorder, spina bifida, hydrocephalus, microcephalus, or muscular dystrophy as a primary disability. Forty-seven percent of respondents endorsed these latter conditions as “additional” disabilities. Nearly half of the sample (46%) rated the overall severity of their disabilities as “mild”; one-third rated their disabilities as “moderate”; and one-fifth (20%) rated their disabilities as “severe.”

Of employed respondents (i.e., 78% of the sample), more were employed part-time (<20 hours per week) than full-time (>20 hours per week). More than half of employed

respondents (58%) worked in sheltered workshops. Twenty-seven percent were in supported employment and just 2% were in competitive employment. Fewer than 1% of respondents were self-employed. Nine percent of the sample (ranging in age from 47 to 93) indicated that they were retired. Almost three quarters of “student” respondents (i.e., 3% of the sample) were over the age of 40.

On average, respondents experienced between seven and eight secondary conditions with the greatest number of persons (n = 74) experiencing three secondary conditions (see Figure 1). More than half of the respondents (54%) reported experiencing 0-6 secondary conditions, 32% reported 7-14 secondary conditions, 11% reported 15-22 secondary conditions, and 3% reported 23-33 secondary conditions.

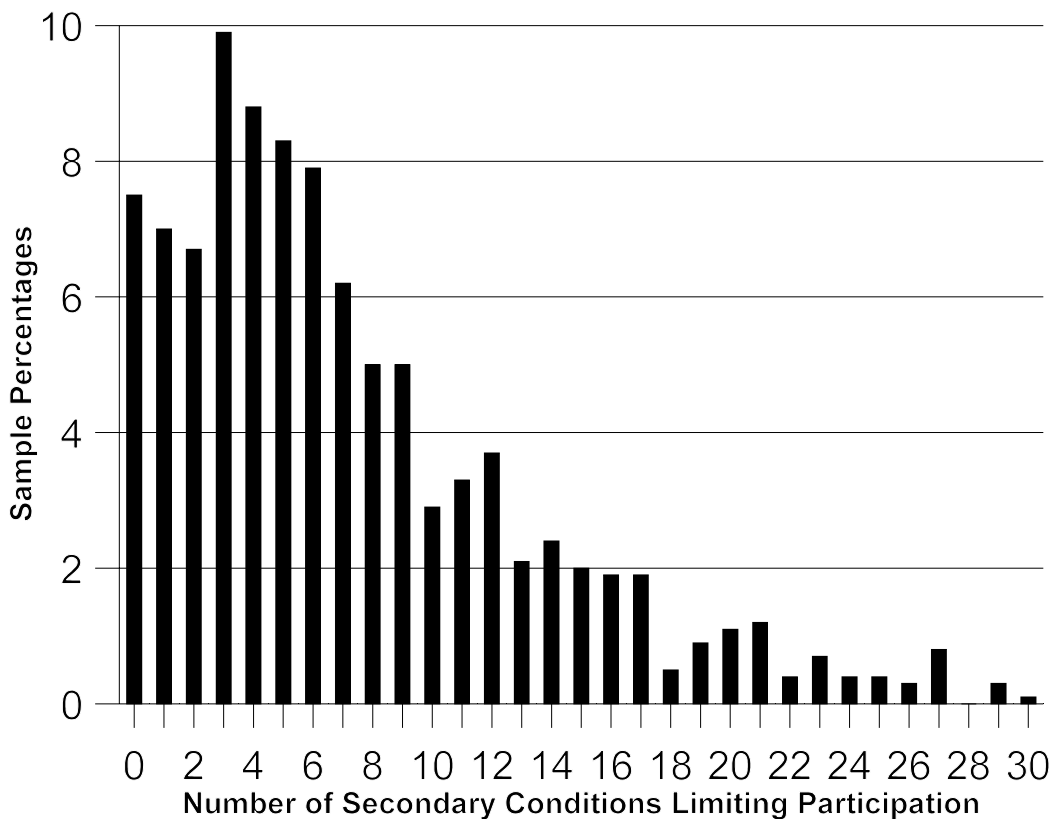


Figure 1. Percentages of respondents across varying numbers of secondary conditions rated as limiting participation at least one hour per week.

The most-severely-limiting secondary condition reported (Avg. Limitation Rating = 2.18) was “Cancer,” followed by “Diabetes” (Avg. Limitation Rating = 2.05) and “Problems with Mobility” (Avg. Limitation

Rating = 1.91). Table 2, on the following page, lists the ratings of secondary conditions, rank-ordered by Problem Index (the most significant problem experienced by the most people).

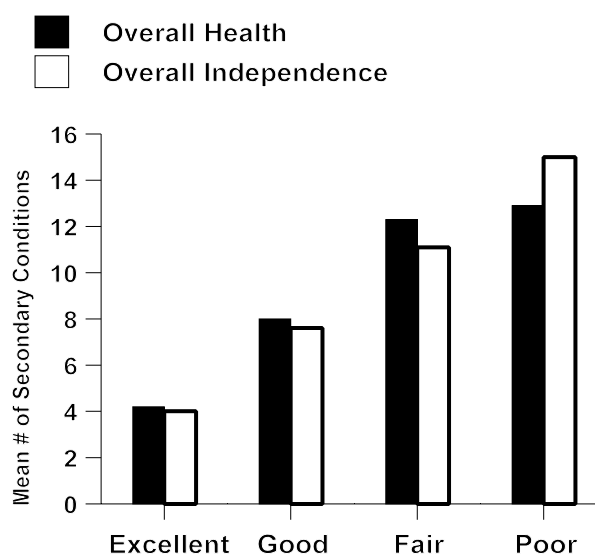
Table 2: Rankings of Secondary Conditions Reported by the Respondents (N =749)

Rank (by Problem Index)	Secondary Condition	% Endorsing	Prevalence/1000	Avg. Severity	Problem Index
1	Communication Difficulties	53%	526	1.80	95
2	Physical Conditioning Problems	47%	466	1.49	78
3	Weight Problems	41%	411	1.62	66
4	Persistence Problems	42%	417	1.56	66
5	Personal Hygiene	41%	407	1.56	64
6	Dental Problems	39%	390	1.64	64
7	Problems with Mobility	28%	281	1.91	54
8	Memory Problems	31%	309	1.59	49
9	Vision Problems	31%	312	1.53	47
10	Joint and Muscle Pain	28%	277	1.65	46
11	Depression	29%	293	1.54	45
12	Fatigue	30%	299	1.47	44
13	Balance Problems	26%	256	1.63	42
14	Sleeping Problems	23%	234	1.52	35
15	Bladder Dysfunction	22%	215	1.54	34
16	Contractures	17%	166	1.76	30
17	Bowel Dysfunction	19%	187	1.55	29
18	Injuries due to Accidents/Seizures	18%	182	1.48	27
19	Injuries due to Self-Abuse	16%	165	1.66	26
20	Access Problems	15%	149	1.70	25
21	Hearing Problems	14%	140	1.76	25

22	Side Effects from Medications	18%	182	1.38	25
23	Arthritis	16%	160	1.51	24
24	Respiratory Problems	14%	139	1.69	24
25	Cardiovascular Problems	15%	148	1.52	23
26	Allergies/Allergic Reactions	16%	158	1.40	22
27	Gastrointestinal Dysfunction	12%	118	1.60	19
28	Scoliosis	9%	93	1.68	15
29	Urinary Tract Infection	11%	110	1.25	14
30	Nutritional Deficits	9%	88	1.60	14
31	Equipment Failures	8%	79	1.76	14
32	Care-related Injuries to Others	8%	83	1.46	12
33	Diabetes	5%	54	2.05	10
34	Osteoporosis	6%	55	1.51	9
35	Care-related Injuries to Consumer	7%	68	1.27	9
36	Pressure Sores	5.5%	55	1.39	8
37	Equipment-related Injuries to Self	3.5%	35	1.71	6
38	Equipment-related Injuries to Others	3%	33	1.48	5
39	Postural Hypotension	4%	36	1.20	5
40	Loss of Sensation	3%	32	1.27	4
41	Alcohol/Drug Abuse	2.5%	25	1.29	3
42	Cancer	2%	16	2.18	3
43	Sexually Transmitted Disease	1%	10	1.43	1
44	Heterotropic Bone Ossification	1%	10	1.28	1
45	Instability of the Neck	1%	10	1.43	1

Respondents rated their overall health and independence on a four-point scale similar to that used to rate secondary conditions. The vast majority of respondents rated their overall health and their overall independence as “good” or “excellent” (85% and 76%, respectively). The relationship between health and independence ratings was significant ($r = .50$). That is, higher ratings of one dimension were statistically related to higher ratings of the other. Additionally, the relationships between the number of secondary conditions experienced as limiting and the ratings of overall health ($r = .42$) and overall independence ($r = .46$) were statistically significant. The greater the number of secondary conditions experienced as limiting (more than one hour of participation per week), the poorer a respondent rated his or her health and independence. These relationships are illustrated in Figure 2.

Figure 2. Relationships between the average number of secondary conditions rated as limiting and overall health and overall independence ratings.



Three Secondary Conditions of Concern for Montanans with Developmental Disabilities: Communication Difficulties, Weight Problems, and Physical Fitness and Conditioning Problems.

Communication difficulties were reported by the largest number of respondents (53%) and were also among the top ten most limiting secondary conditions. The negative impacts that this condition can have on important domains of daily living also highlight it as a critical area of concern for adults with developmental disabilities. These influences are discussed below in terms of the data.

The second and third most commonly reported secondary conditions were “Weight Problems” (41%) and “Physical Fitness and Conditioning Problems” (47%). Not surprisingly, these latter two secondary conditions have a statistically significant relationship ($r = .61$). As limitation associated with one condition increased, limitation associated with the other also increased. Results further describing their relationship are discussed below.

Communication Difficulties. When respondents were asked what percentage of an average day they could communicate effectively, only 38% estimated that they could communicate effectively in all daily living

settings at all times. One-eighth of participants estimated their communication to be effective less than 50% of a typical day.

Assistive technologies have great potential for reducing limitation due to

communication problems, yet only 3% of the sample reported using communication devices such as communication boards, voice output systems, or computerized output system. Many low tech and inexpensive communication support systems are available to address this critical need.

Interestingly, self-employed persons and those in supported and competitive employment settings were able to communicate effectively across a larger

percentage of a typical day than sheltered workshop employees ($t(492.82) = -2.76, p < .05$). Figure 3 shows the percentage of a typical day individuals could communicate effectively and compares within each level of effectiveness, the percentage of sheltered workshop employees to the percentage of self-employed, competitive employees, and supported employees.

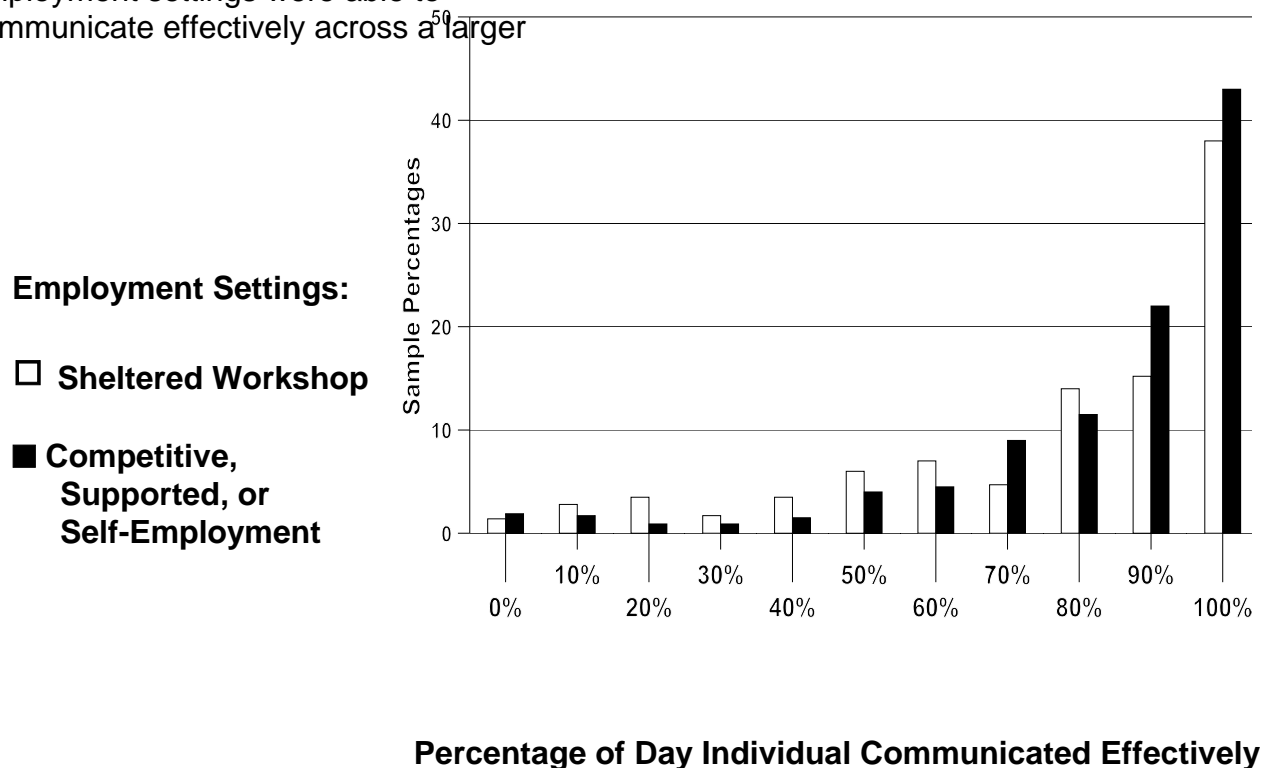


Figure 3. Average communication effectiveness of community-based and sheltered workshop employees.

Weight problems are important because weight is related to overall health and independence.

According to the National Heart, Lung and Blood Institute, a body mass index (BMI) is strongly correlated with total body fat in adults. BMI is calculated by multiplying a person's weight by 700 and dividing that number by his or her height in inches squared. Height/weight data from annual planning assessments were

available for a large number of respondents (i.e., N = 706), allowing us to calculate their BMIs.

Figure 4 illustrates the distribution of our sample across the varying levels of calculated BMIs. For the subset of respondents for whom we calculated BMI, 6.4% of consumers were underweight (BMI < 18.5). More than half were overweight (BMI > 25), and more than a quarter of these persons were obese (BMI > 30).

Given the Federal guidelines on identifying, evaluating and treating overweight adults and obesity (National Institutes of Health, 1998), the large number of persons who were overweight and obese is alarming. These guidelines are based on research showing that risk for cardiovascular and other diseases rises significantly when BMI is 25 or over and the risk of mortality increases when BMI is 30 and above.

Along with these concerns, our data show that for persons with mobility impairments, being overweight or obese may also increase demands on assistance

activities such as transfers and position changes. This may function as a risk factor affecting consumer participation. Specifically, statistical analyses demonstrated that experiencing moderate or significant limitation due to mobility problems and having higher BMIs were both positively related to greater experience of care-related injuries to others. These patterns suggest that weight reduction behaviors may have added benefits for persons limited by mobility problems.

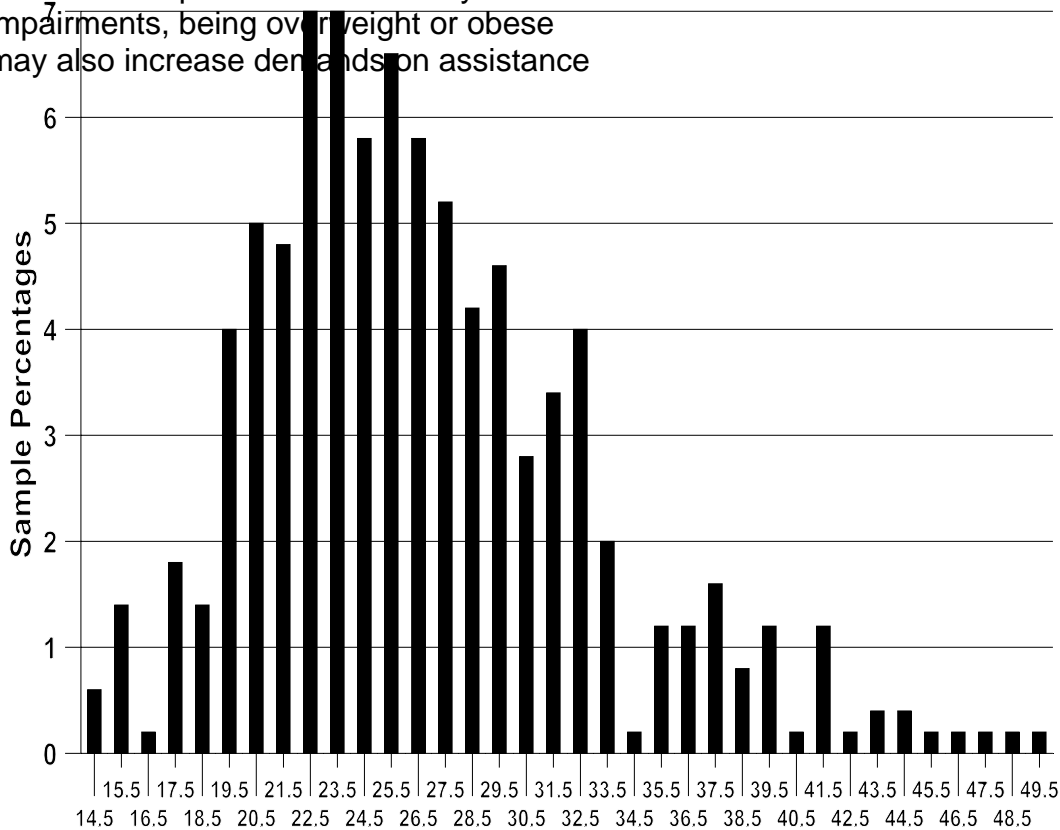


Figure 4. Sample's distribution of Body Mass Indices (BMI).

Respondents' body mass indices were statistically related to the amount of limitation associated with the secondary condition, "Weight Problems", as estimated on the survey's 4-point rating scale. Still, some individuals meeting the BMI criteria for

underweight, overweight and obesity did not indicate that they experienced any limitation

associated with their weight problems (see Figure 5).

This survey also asked for subjective classification of respondents' body weight. Two percent of respondents were described as "very underweight"; 12 % were "somewhat underweight"; 43% were "about the right weight"; 33% were

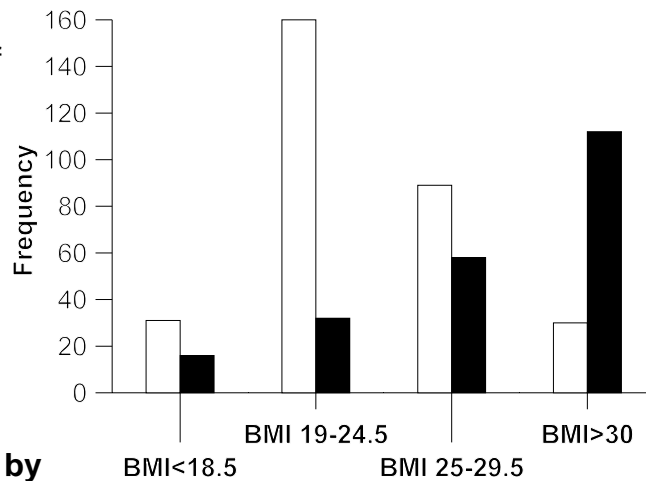


Figure 5: Persons limited or not limited by

weight problems according to whether their BMIs met the 1998 National Heart, Lung, & Blood

Institute's criteria for underweight, acceptable weight, overweight, and obese.

respective average BMIs of 29 and 37. At the same time, the ranges of BMI within

"somewhat overweight"; and 10% were described as "very overweight." Calculated BMIs reveal discrepancies that indicate an area for potential intervention. That is, persons described as "very underweight" or "somewhat underweight" had average BMIs of 21 and 20; persons described as "about the right weight" had an average BMI of 24; and persons described as "somewhat overweight" and "very overweight" had

these five categories suggest that some persons meeting the objective criteria for being underweight or overweight do not perceive themselves as being underweight or overweight or are not perceived as such by their direct care providers.

For individual and state planners designing programs to increase health and participation, these data begin to create a picture. If secondary condition prevention programs are to succeed, weight reduction goals are relevant and important.

Physical fitness and conditioning problem descriptions were statistically related to weight problem descriptions in ways that may provide additional insight into the design of health promotion programs. For instance, the survey data describing the sample's levels of cardiovascular and sedentary activity revealed opportunities to increase activity to beneficial levels. Ratings from the sample were distributed somewhat symmetrically across an 8-point rating scale that ranged from zero (respondent was "very active" on an average day) to seven (respondent was "very sedentary" on an average day; see Figure 6). Alarming, over one-half of the sample (51.9%) estimated that on an

average day, they were more sedentary than active. These ratings were significantly related to the amount of limitation associated with both physical fitness and conditioning problems ($r = .42$) and weight problems ($r = .29$).

To obtain substantial health benefits, the Centers for Disease Control and Prevention and the American College of Sports Medicine recommend every adult accumulate 30

minutes or more of moderate-intensity physical activity on most, preferably all, days of the week. The emphasis is on physical activity of moderate-intensity. Examples of such

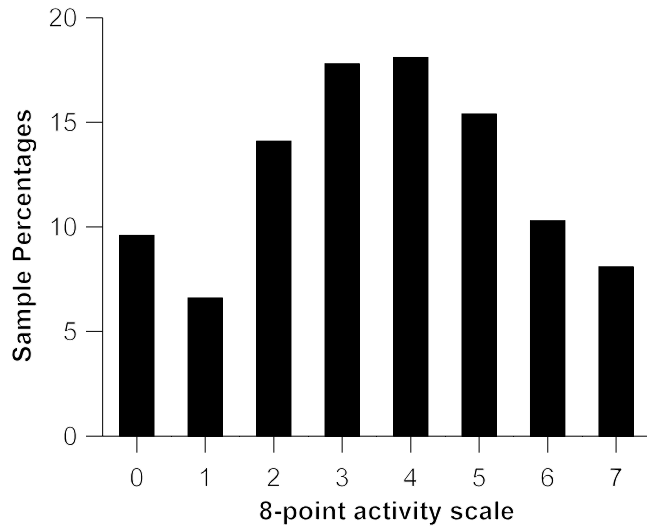


Figure 6. Sample distribution across

ratings of activity level on average day (8-point scale ranging from zero (“very active”) to seven (“very sedentary”).

**Very
Active**

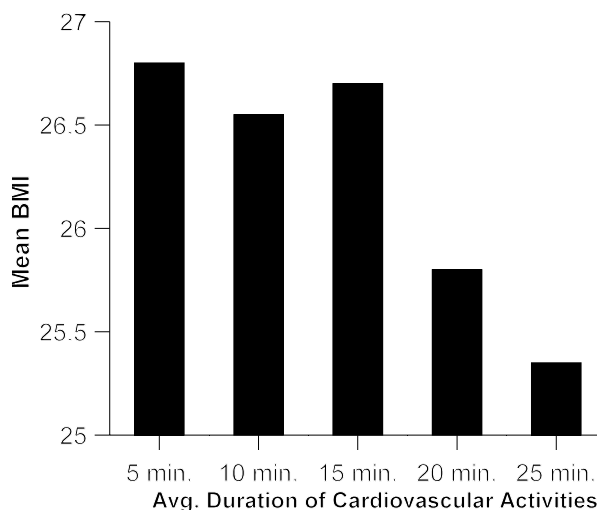
**Very
Sedentary**

activity includes walking briskly (3-4 mph), cycling for pleasure or transportation (<=10 mph), swimming, calisthenics, table tennis, golf, fishing, canoeing, home care, lawn mowing, and home repair. Scientific studies have shown that any combination of these activities performed over the course of a day for a cumulative total of 30 minutes will result in substantial health benefits, including a decreased risk of mortality. Of the four-fifths of respondents to the survey who raised their heart rates during physical activity on at least one day a week: 31% did so just one or two days each week; another 31% did so three or four days each week; 23% did so five or six days each week; and only 15% raised their heart rates every day. There was a significant, positive relationship between the number of days each week persons raised their heart rates and the number of minutes they exercised. This relationship is reflected in the small number of respondents (18%) who performed heart-rate-raising activities for twenty-five minutes or more each week. With appropriate individualized planning, many respondents could increase the frequency and duration of heart raising activities to achieve greater participation and long-term health benefits.

The number of minutes that respondents raised their heart rates was also related to their average BMIs (see Figure 7). Though the average BMI stayed in the “overweight” range across each subgroup, these averages decreased as average duration of heart-rate-raising activity increased. This assessment also indicated that overall ratings of activity level on an average day (8-point scale) were significantly related to BMI, so that respondents rated as more sedentary had higher BMIs. Implementing these types of assessments within an ongoing surveillance system will greatly inform these and other relationships between hallmark risk and protective factors, as well as better inform the experience of

secondary conditions among adults with developmental disabilities.

Figure 7: Average BMIs of persons in heart-rate-raising activities at least one day per week across the average amount of time they maintained such activities.



On a final and related topic, only 9% of respondents indicated that the secondary condition, nutritional deficits, was associated with some amount of limitation, and the average severity of reported limitation associated with this condition was moderate (1.60). However, many of the reported secondary conditions are associated with under- or over-nutrition in the general population: physical conditioning and weight problems, dental problems, depression, fatigue, alcohol abuse, bladder dysfunction, bowel dysfunction, gastrointestinal dysfunction, side effects of medication, allergies, diabetes, cancer, osteoporosis, and cardiovascular disease. RTC: Rural plans further research on the dietary intake of adults with developmental disabilities and its effects on participation.

Conclusions

Ten of the top twelve secondary conditions reported by respondents involved issues that are related to wellness or lifestyle management. These and other secondary conditions can also be positively affected by behavior management strategies. Additionally, health promotion research is pointing more and more to self-determination as a consequential component of successful programs.

Federal guidelines (e.g., *Healthy People 2010*) on lifestyle management can serve as a starting place for assessing and addressing individual weight control problems and the need for physical conditioning activities. Scientific reports and articles provide additional information and results that can be very relevant and encouraging for adults with developmental disabilities. For instance, the CDC and the American College of Sports Medicine summarized scientific evidence indicating that: sedentary individuals benefit most by increasing their activity to recommended levels; most health benefits can be achieved by increasing activity outside of formal exercise programs; and some persons with disabilities can achieve recommended activity levels with associated health benefits by performing daily living activities with supports that facilitate the greatest degree of independence.

The use of behavior management techniques may directly address pain, sleep disturbances, depression, and fatigue. Individuals with developmental disabilities can incorporate wellness and healthful activities in their lives to increase control

over their own lives and choices. Used in concert, wellness strategies and behavior management techniques may provide the individual, and his or her support circle, with a variety of options to ameliorate the effects of weight and conditioning problems.

In order for these strategies and techniques to work, individuals must be able to communicate their wants and needs. Individualized strategies and techniques designed to facilitate consumer control and decision-making should directly address "Communication Problems." Additionally, the ability to communicate effectively about one's own health is critical to securing, evaluating, and modifying appropriate prevention and treatment strategies.

The success of RTC: Rural's *Living Well with a Disability* health promotion program for people with disabilities was the impetus for our exploration of ways in which health promotion activities might improve the health and lives of individuals with developmental disabilities. *Living Well with a Disability* starts with the premise that people with disabilities are not "sick". Everyone has a right to feel well and enjoy an active life. The program uses existing community resources, and encourages individual goal-setting and the lifestyle changes that lead to the accomplishment of those goals. It is our belief that people with developmental disabilities can also be well, articulate their goals, and work to make those goals a reality.

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<http://wonder.cdc.gov/wonder/prevguid/p0000391/p0000391.asp>

Resources

American Speech-Language-Hearing Association, 10801 Rockville Pike, Rockville, Maryland 20852; 800-498-2071, 301-897-5700 (TTY), 301-571-0457 (Fax); professional.asha.org/

ASHA is a professional, scientific, and credentialing association for more than 99,000 speech-language pathologists, audiologists, and speech, language, and hearing scientists in the U.S. and internationally. ASHA promotes the highest quality services for professionals in audiology, speech-language pathology, and speech and hearing science, and it advocates for people with communication disabilities.

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Healthy People 2010, Office of Disease Prevention and Health Promotion, HH Humphrey Bldg, Rm 738G, 200 Independence Avenue, SW., Washington,

DC 20201; Fax 202-205-9478;
www.health.gov/healthypeople/default.htm

A set of health objectives for the Nation to achieve over the first decade of the new century. It can be useful to many in the development of programs to improve health.

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Chapter 6, Volume I. Available:
www.health.gov/healthypeople/document/html/volume1/06disability.htm

Living Well with a Disability, Rural Institute on Disabilities, University of Montana, 52 Corbin, Missoula, MT 59812-7056; 406-243-2468;
raves@selway.umt.edu;
www.livingwellweb.com/lwpage1.htm

An eight-week workshop using goal setting and problem solving as the framework for developing healthy lifestyles. Participants report improvement in outlook and positive changes in daily activity, such as new recreational pursuits or returning to school. Many learn they can pursue meaningful goals despite limitations, and finally, a sense of belonging develops as participants feel accepted and encouraged by peers.

National Health Information Center, P.O. Box 1133, Washington, DC 20013-1133; 800-336-4797, 301-565-4167, 301-984-4256 (Fax); info@nhic.org (E-mail), www.health.gov/nhic

Helps the public and health professionals locate health information through identification of resources, information and referral, and publications. Uses a database to refer inquirers to the most appropriate resources. Does not diagnose medical conditions or give medical advice. Prepares and distributes publications and directories on health promotion and disease prevention topics.

Prader-Willi Syndrome Association, 5700 Midnight Pass Rd., Sarasota, FL 34242; 800-926-4797; 941-312-0400, 941-312-0142; www.pwsausa.org, pwsausa@aol.com

Organized in the United States in 1975 to serve as an international vehicle of communication about Prader-Willi Syndrome (PWS), a genetically based developmental disability. Its mission: "to provide to parents and professionals a national and international network of information, support services, and research to expressly meet the needs of affected children and adults and their families."

RTC:Rural, Research and Training Center on Rural Rehabilitation Services, The University of Montana Rural Institute, 52 Corbin, The University of Montana, Missoula, MT 59812-7056; 888-268-2743 (toll-free), 406-243-5647 (V/TT); ruralinstitute.umt.edu/rtrcrural/health/DDisHPro.htm

The health promotion projects serve persons with developmental disabilities, and address secondary conditions that limit their independence and participation. The focus of these projects is the development of a system of health monitoring and promotion that may be implemented within service delivery networks supporting adults with developmental disabilities. Currently, projects are focusing on ways in which consumers' wellness and quality of life can be influenced by key characteristics of formal support persons (e.g., case managers, direct service staff, health care professionals).

For more information about this survey and the RTC:Rural, contact:

Meg A. Traci, Ph.D., Project Director, Research and Training Center on Rural Rehabilitation Services, The University of Montana Rural Institute, 52 Corbin Hall, The University of Montana, Missoula, MT 59812-7056; 888-268-2743 (toll-free), 406-243-5647 (V/TT), 406-243-4956 (Meg's office); <http://ruralinstitute.umt.edu/rtrcrural/health/DDisHPro.htm>

