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Health and Wellness among Adults with Developmental Disabilities

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In 1988, the National Council on Disability published ***Toward Independence***, which identified the prevention of secondary conditions and health promotion for people with disabilities as a major national goal. During the last ten years this goal has grown in importance, with U.S. service corporations and agencies, researchers, policy makers, and even private industry acknowledging its wisdom. An entire section of *Healthy People 2010*, the nation's blueprint for promoting the health of the entire population, addresses disability and health. Previous editions in the series contained no explicit sections on disability. Now, disability has its own section, with 12 specific objectives and related objectives in other major sections.

A health and wellness perspective on disabilities is consistent with independent living philosophy. It assumes that people with disabilities can lead healthy and independent lives, and are often the best managers of their own health.

What do health and wellness mean for people with developmental disabilities? We believe the attention researchers are giving to health and wellness parallels past emphases on the importance of recreation, community integration, consumer advocacy, and supported employment.

The 1970s deinstitutionalization movement implicitly assumed that community medical service providers would be responsible for the health of people with disabilities. However, as the contexts of medical and health care services change significantly, "health" is defined much more broadly than just as "medical services".

People with developmental disabilities must be seen as participants in preventing secondary conditions, as well as managing existing secondary conditions. Purely medical management is not as effective. Many service providers believe that as adults with developmental disabilities move to less restrictive living environments, the risks associated with developing secondary conditions increase. Therefore, each person's Individual Plan must measure and include his or her health preferences and goals.

Research Goals

There is relatively little empirical information about secondary conditions, health, or wellness among people with developmental disabilities. Such information is important for understanding the extent to which secondary conditions cause limitation and affect health and wellness. Information on any risk factors preceding the onset of limitation is also scarce but crucial.

The Research & Training Center on Rural Rehabilitation conducts applied research designed to build upon the strengths of rural individuals and communities to solve the problems of daily life. This series of reports makes research results available as soon as is practical. Note that data presented are preliminary and must be interpreted with caution. The major limitations are reported. Please contact project staff to discuss issues presented.

The goals of our research include:

1. Survey all consumers of Montana DD services to collect data about their health,

secondary conditions, and risk factors;
2. Develop and pilot test multi-media computer software which enables consumers to make their own health preferences; and
3. Use both sets of information to develop standards of care for local and national dissemination.

Key Terms and Concepts

Disability is a limitation in performing socially defined activities and roles expected of individuals within a social and physical environment (Pope & Tarlov, 1991). Secondary conditions may cause additional limitations which affect a person's ability to live a happy, fulfilled life.

Health is more than the absence of disease. It is a physical and mental state which allows maximum goal achievement and independence. Health is a means to attaining a goal, rather than a goal in itself.

A **Secondary Condition** occurs when a person with a disability develops a complication related to his or her impairment (Marge, 1988). Measured in "hours of limitation per week", the secondary condition adversely affects health and independence.

Wellness is a way of living or a lifestyle that achieves a person's potential for health and independence.

Risk Factor is any physical, social, environmental, or behavioral factor that disposes a person to develop secondary conditions.

Research Process

We developed our assessment instrument items in collaboration with representatives of the Montana Developmental Disabilities Planning and Advisory Council, the Montana Disabilities Division's Health Care Task Force, the Montana Developmental Disabilities Program, the Montana Association for Independent Service Providers, and many generous direct care service providers and consumers.

Our instrument is designed to be completed by someone very familiar with an individual consumer (e.g. a direct care provider or family member). Interrater reliability estimates for the secondary condition items are very high, averaging 89% (n = 11). We now have 267 completed surveys, including 156 which include risk factors.

Preliminary Findings

Figure 1. Most Commonly Reported and Problematic Secondary Conditions Among Adults with Developmental Disabilities (n = 267)

1. Communication Difficulties
2. Persistence Problems/Low Frustration Tolerance
3. Over/Under Weight
4. Poor Personal Hygiene/Appearance
5. Poor Physical Fitness & Conditioning
6. Fatigue
7. Inadequate Dental Hygiene
8. Sleep Problems/Disturbances
9. Poor Balance/Dizziness
10. Joint and Muscle Pain
11. Contractures
12. Bowel Dysfunction
13. Bladder Dysfunction
14. Depression
15. Mobility Impairment

*Note: Each condition is intrinsically related to an individual's behavior or lifestyle.

Figure 1 lists the fifteen most problematic secondary conditions reported by our pilot sample.

Figure 2. Association Between Limitation Due To Physical Fitness & Level of Sedentariness (n=154, 0= Very Active & 7=Very Sedentary) In Persons With Developmental Disabilities

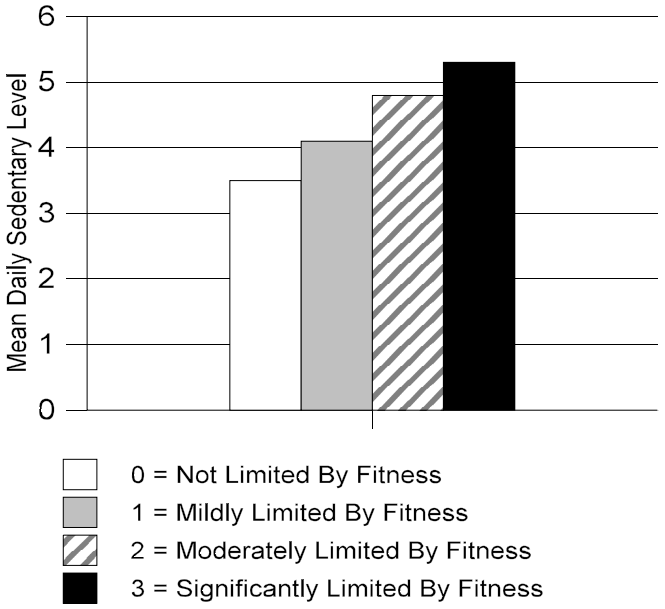


Figure 2 illustrates how these data may describe the associations between risk factors and limitation due to secondary conditions. Specifically, Figure 2 illustrates the direct relationship between individuals' limitations resulting from physical fitness problems and their levels of sedentariness.

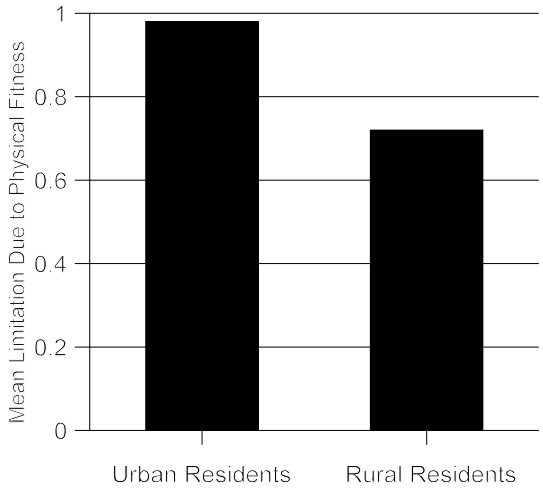
Figure 3. Statistics on Health Care Utilization (n=154)

- ✔ **94%** had received a general physical exam.
- ✔ Average of **7.4** annual physician visits
- ✔ **13%** had been admitted to a hospital.
- ✔ **27%** had been admitted to the ER.
- ✔ Average hospital stay of **8.9** days
- ✔ Average of **1.2** annual preventive dental visits
- ✔ **49%** take three or more medications
- ✔ **36%** use assistive mobility devices
- ✔ **50%** of women over age 40 had received an annual breast exam.
- ✔ **26%** of men over age 40 had received an annual prostate exam.

Figure 3 summarizes health care utilization data. It will be important to track this over time, relate it to limitation due to secondary conditions, and compare it to information from other populations of individuals.

Figure 4 illustrates limitation differences experienced by urban residents and by rural residents. Urban residents from the pilot sample experienced significantly more limitation due to poor physical fitness than did residents of rural areas.

Figure 4. Limitation Due to Physical Fitness in Persons With D.D. Living in Urban & Rural Montana counties (Scale of 0 to 3, t(261)=2.07*)



Important Limitations

Several limitations should be considered when interpreting our results. These include:

1) The relationships between risk factors and secondary conditions are purely correlational. All data was collected at one point in time, so one cannot interpret causal relationships;

2) While the inter-rater reliability estimates for the secondary conditions measures are high, we have not yet estimated the reliability of the risk factor measures;

3) Data are not based on a random sample. Direct care staff chose most participants.

Next Steps

We are reviewing our preliminary data for completeness, and are assessing the validity and reliability of our measurement instrument. We will eliminate redundant items or those with little relationship to our measures of limitation due to secondary conditions. When the instrument is complete, we will administer a statewide survey of everyone receiving DD services in the state of Montana. We expect data from that effort to be available by Fall, 1999.

We have also collected Inventory for Client and Agency Planning (ICAP) data on our current survey participants. The ICAP is a skills based inventory used to write annual individual plans for people receiving DD services. Analyses of our current data combined with the ICAP will allow us to determine the relationships between motor skills, social and communication skills, personal living skills and community living skills, and limitation due to secondary conditions.

During 1999, we will also develop and pilot test a multi-media computer program to study the health choices of people with developmental disabilities. Using the data generated from both the survey and the computer program, we will formulate standards of care for use in various living situations, including group homes.

References and Resources

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