Life changes as possible predictors of secondary conditions

Meg Ann Traci

The University of Montana

Follow this and additional works at: https://scholarworks.umt.edu/etd

Let us know how access to this document benefits you.

Recommended Citation

Traci, Meg Ann, "Life changes as possible predictors of secondary conditions" (2000). Graduate Student Theses, Dissertations, & Professional Papers. 10619.
https://scholarworks.umt.edu/etd/10619

This Dissertation is brought to you for free and open access by the Graduate School at ScholarWorks at University of Montana. It has been accepted for inclusion in Graduate Student Theses, Dissertations, & Professional Papers by an authorized administrator of ScholarWorks at University of Montana. For more information, please contact scholarworks@mso.umt.edu.
INFORMATION TO USERS

This manuscript has been reproduced from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.

The quality of this reproduction is dependent upon the quality of the copy submitted. Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps.

Photographs included in the original manuscript have been reproduced xerographically in this copy. Higher quality 6" x 9" black and white photographic prints are available for any photographs or illustrations appearing in this copy for an additional charge. Contact UMI directly to order.
Permission is granted by the author to reproduce this material in its entirety, provided that this material is used for scholarly purposes and is properly cited in published works and reports.

**Please check "Yes" or "No" and provide signature**

Yes, I grant permission

No, I do not grant permission

Author's Signature: [Signature]

Date: 12/21/00

Any copying for commercial purposes or financial gain may be undertaken only with the author's explicit consent.
LIFE CHANGES AS POSSIBLE PREDICTORS OF SECONDARY CONDITIONS

by

Meg Ann Traci

B.S. The University of Wisconsin- Madison, 1990

M.A. The University of Montana, 1998

presented in partial fulfillment of the requirements

for the degree of

Doctor of Philosophy

The University of Montana

December, 2000

Approved by:

Co-chairperson: Kimberly Wallace, Ph.D.

Co-chairperson: Tom Seekins, Ph.D.

Dean, Graduate School: David Strobel, Ph.D.

Date

12-21-00
The current research investigated the relationships between life change and the experience of secondary conditions among adults with developmental disabilities. As such, it represented a confluence of two streams of health promotion research, one defined by its focus on the disablement process associated with secondary conditions among persons with disabilities (Marge, 1988; Pope & Tarlov, 1991) and the other by its focus on the health-related effects of stress and coping (Holmes & Rahe, 1967; Folkman & Lazarus, 1984; Antonovsky, 1991). Results of regression analyses indicated that the hypothesized positive relationship between life changes and the frequency of secondary conditions was significant, whereas the relationship between life changes and the sum of severity ratings associated with secondary conditions approached significance. Although life changes accounted for a small proportion of the variance in the experience of secondary conditions, these results are consistent with previous descriptions of the relationship between life changes and health in other populations (Thoits, 1983). Preliminary investigations exploring the potential utility of personal and environmental attributes for further describing the relationship between life change and the experience of secondary conditions were also conducted. These were framed within general exploratory hypotheses positing the importance of cumulative and compensatory effects to the prediction of the experience of secondary conditions. Classification and Regression Tree (CART; Breiman, Friedman, Oshen, & Stone, 1984) analyses were used to test these hypotheses. CART generated two models predicting profiles of individuals with different frequencies of secondary conditions experienced as limiting and different severity estimates for the limitation due to secondary conditions. These models provided support for the exploratory hypotheses of the present study. They illustrated the importance of looking beyond traditional bivariate descriptions of the relationships between predictors and outcome variables to potential compensatory and cumulative effects of predictive factors on the experience of secondary conditions. The exploratory analyses suggested that, in terms of secondary conditions, younger persons with lower overall disability severity may adapt more successfully to life change than do older persons with greater overall disability severity. Given the preliminary nature of these findings, implications are discussed primarily in terms of future research directions.
# TABLE OF CONTENTS

INTRODUCTION ................................................................. 1  
Rationale ................................................................. 3  
   A growing population ........................................ 3  
   Economic and social relevance ...................... 6  
   Vulnerability of persons with developmental disabilities 7  
Stress ................................................................. 10  
Secondary conditions and prevention .................. 13  
   IOM conceptual model ............................... 15  
Health, risk and protective factors ..................... 17  
Exploratory analyses ........................................... 21  
Exploratory Hypotheses ...................................... 25  

METHOD ................................................................. 26  
Participants ......................................................... 26  
Power Analysis .................................................... 28  
Instrumentation .................................................... 30  
Demographics ...................................................... 33  
Data Analysis ....................................................... 34  

RESULTS ................................................................. 38  
Descriptive Statistics ............................................ 38  
Regression Analyses ............................................ 39  
Exploratory Analyses .......................................... 43  

DISCUSSION ............................................................. 58  
The Role of Stress in Health Promotion with Adults with MR/DD 69  
Caveats, Limitations, and Future Research Directions 73  
Conclusions .......................................................... 80  

REFERENCES ........................................................... 81  

APPENDICES  
APPENDIX A: MONTANA HEALTH AND HUMAN SERVICES 
   DEVELOPMENTAL DISABILITIES PROGRAMS FOR ADULTS .. 97  
APPENDIX B: POWER ANALYSIS .................................. 107  
APPENDIX C: THE HEALTH AND SECONDARY CONDITIONS 
   SURVEILLANCE INSTRUMENT FOR ADULTS WITH 
   DEVELOPMENTAL DISABILITIES .......................... 109  
APPENDIX D: RELIABILITY ESTIMATES OF THE SECONDARY 
   CONDITIONS SURVEILLANCE INSTRUMENT ............ 127  
APPENDIX E: DETAILED DESCRIPTION OF REGRESSION ANALYSES 131  
APPENDIX F: VALIDATION OF MODELS 1 AND 2: REGRESSION 
   ANALYSES OF DATA FROM AN INDEPENDENT SAMPLE OF 
   ADULTS WITH DEVELOPMENTAL DISABILITIES ........ 136
LIST OF FIGURES

Figure 1. Institute of Medicine's (IOM) Model of Disablement. ......................... 16
Figure 2. Example of a Regression Tree ............................................................. 36
Figure 3. Optimal regression tree modeling the frequency of secondary conditions and the sum of severity ratings associated with secondary conditions. All predictors were considered. ................................................................. 46
Figure 4. Optimal regression tree modeling the sum of severity ratings associated with secondary conditions. The predictor, number of individual plans was excluded from the analysis. ............................................................... 50
Figure 5. Optimal regression tree modeling the validation sample data for the sum of severity ratings associated with secondary conditions. Number of individual plans was excluded from the analysis. ......................................................... 55
Figure 6. Optimal regression tree modeling the independent sample data for frequency of secondary conditions. Number of individual plans was excluded from the analysis. ... 57

LIST OF TABLES

Table 1. Sample characteristics. .............................................................................. 29
Table 2. Means and Standard Deviations by Gender and Correlations Between Age, Frequency of Secondary Conditions, and Sum of Severity Ratings Associated with Secondary Conditions. ................................................................. 39
Table 3. Summary of Regression Analyses (nontransformed data) ....................... 42
Table A1. Approximate Number of Montanans with Mental Retardation or a Developmental Disability Receiving Different Types of Services ........................................ 103
Table E1. Summary of Regression Analyses (transformed data). .......................... 134
Table F1. Means and Standard Deviations by Gender and Correlations Between Age, Frequency of Secondary Conditions, and Sum of Severity Ratings Associated with Secondary Conditions (validation sample) ........................................... 140
Table F2. Summary of Regression Analyses (validation sample) ......................... 142
Life Changes as Possible Predictors of Secondary Conditions

Primary disabilities are commonly complicated by additional physical and/or psychological problems. Under an important, emerging framework of health promotion with persons with disabilities, these health problems are referred to as secondary conditions (Brandt & Pope, 1997; Marge, 1988; Pope & Tarlov, 1991). The number of persons with severe disabilities was estimated as 24.1 million for the years 1991-1992 (McNeil, 1993). This population was prospectively estimated to have increased to 25.2 million persons in the year 1995 (Innes et al., 2000). Within this population are approximately 2-4 million persons who have a developmental disability (LaPlante, 1989). Some of the most common developmental disabilities are: mental retardation, cerebral palsy, fetal alcohol syndrome and exposure, Down syndrome, autism, epilepsy or seizure disorder, hydrocephaly, microcephaly, and muscular dystrophy. Secondary conditions associated with one or more of these disabilities include psychological problems such as depression, environmental problems such as access, and medical conditions such as pressure sores and urinary tract infections (Lollar, 1994; Seekins, Smith, McCleary, Clay, & Walsh, 1991; World Health Organization, 1999). Until recently, it was common to conceptualize these ailments as symptomatic of the primary disability; however, it is presumed that because these conditions can be prevented or managed, they are secondary conditions distinct from the symptoms of the primary disability. Research is needed to identify and test the generalizability of theories (e.g., Antonovsky, 1991; Rutter, 1987; Seligman, 1975) and relevant findings (for a review of examples from the literature on lifespan development, see Staudinger, Mariske, & Baltes, 1995) guiding current prevention
programs for the general population to programs of health promotion with persons with
disabilities. For example, theories of stress predicting its role in individuals’ health and
well-being could be very informative to the prevention of secondary conditions, yet their
application in populations with disabilities has been limited. The current study was
designed to address this limitation in the literature by exploring the relationship between
stress and secondary conditions among adults with developmental disabilities.

Research has shown that stressful life events, either positive or negative, are
associated with increased vulnerability to injuries, poor psychosocial health, and diseases
(Bramwell, Masuda, Wagner, & Holmes, 1975; Cohen, 1988; Cohen, Tyrell, & Smith,
1993; Dohrenwend, 1973; Dohrenwend, Krasnoff, Askenasy, & Dohrenwend, 1978;
Additionally, research has identified factors that can influence the impact of stressful life
events on health (Folkman & Lazarus, 1984; Holmes, 1989; Wallace, 1999). There is a
lack of research, however, regarding the measurement of stressful life events among adults
with developmental disabilities, the ability of life events to predict secondary conditions in
any population, and the potential buffers (e.g., personal and psychosocial attributes) that
ameliorate the negative effects of life events on the experience of secondary conditions
among adults with developmental disabilities.

For the purposes of the present study, secondary conditions were defined as
additional health problems experienced after the acquisition of the primary disability
(Marge, 1988). Also, for the purposes of this study, the term, experience of secondary
conditions was used to refer to the number of secondary conditions limiting the
participation of consumers and to the sum of severity ratings associated with specific secondary conditions. The primary goal of this study was to demonstrate the predictive utility of stressful life events for the experience of secondary conditions among persons with developmental disabilities. A second goal of the study was to describe the potentiating, compensatory, and cumulative effects of life changes as well as personal and environmental factors (i.e., age, gender, residential living arrangement, level of disability severity, number of individual plans related to secondary conditions, and county of residence's urban-rural classification) on the experience of secondary conditions. Results of the exploratory analyses will be used to inform future research that is needed to understand the broad risk and protective factors operating in this population. The rationale for this study is discussed below. Additionally, theories of stress and life changes, conceptual models for studying health problems associated with primary disabilities, as well as developmental perspectives on the study of risk and protective factors are reviewed. Finally, personal and environmental factors associated with the population and theories that suggest how these factors serve a protective function are discussed.

Rationale

A growing population. There is an increasing number of persons with developmental disabilities and therefore, an increasing demand for supports and services. Adults meeting eligibility requirements for developmental disability services are supported through state and local partnerships with community service providers. Between the years 1977 and 1999, the number of individuals eligible for and receiving residential services increased 45.8%, from 247,780 to an estimated 361,172 nationally. On June 30, 1999,
these services were being provided in 113,633 residential settings (Prouty & Lakin, 2000).

Davis (1997) reported that despite the number of services being provided, there were an alarming 35,862 service requests for residential or day/vocational services pending on 1997 waiting lists compiled by state agencies serving individuals with mental retardation.

For several reasons, the needs for services are projected to escalate in the future in both number and kind. These growth trends are predicted across other populations of disabilities as well and are contributing to the 'changing universe of disability' (Seelman & Sweeney, 1995).

Hodapp & Dykens (1996) summarized research on important contributors to the population growth of persons with mental retardation and to an expansion in etiologies accounting for cognitive impairments among future generations of adults with mental retardation. These sources include medical advancements that promote the survival rates and aging of individuals with mental retardation as well as societal problems (e.g., pediatric AIDS, maternal drug abuse, and poor prenatal care) that increase the likelihood of impaired cognitive development among specific individuals (for a further review, see Seelman & Sweeney, 1995). Also, a growing body of research points to environmental toxins as additional sources contributing to the expansion of populations with cognitive impairments (for a review see, Schettler, Stein, Reich, Valenti, & Wallinga, 2000). Lastly, evolving policy and changing eligibility criteria could contribute to larger populations of adult consumers of government support programs. At the state level, Olsen and Price (1997) reported that there are approximately 2,184 adult Montanans with developmental disabilities receiving state developmental disability program (DDP) services or in nursing homes and on
a waiting list for services. Olsen and Price (1997) suggested that if Montana were to match the state definition to the federal definition of developmental disabilities, Montanans with a full range of developmental disabilities and associated functional limitations (i.e., Montanans with developmental disabilities not associated with mental retardation or cognitive impairments) would be eligible for DDP services. They estimated that agency planners could anticipate a caseload increase between 4 and 4.5 times the current count, which corresponds to an increase between 8,736 and 9,828 individuals who would be eligible for services (for more information on Montana developmental disabilities programs for adults, see Appendix A). Moreover, when one considers the predicted increases in the populations of individuals with developmental disabilities not associated with cognitive impairments (Seelman & Sweeney, 1995), Olsen and Price's projected estimate seems conservative. For example, the National Center for Youth with Disabilities (NCYD) reported that, primarily because of improvements in medical technology and science, between the years 1975 and 1995, survival rates for prevalent developmental disabilities such as cystic fibrosis and spina bifida increased dramatically-700% and 200%, respectively (NCYD, 1995). As a result, NCYD (1995) was predicting that one million young adults with chronic illnesses or disability would transition to adult services by the end of the year 2000. Many of these individuals would be eligible for adult programs and services under the federal definition of developmental disabilities but not under the current Montana definition. Since it is unlikely that there will be a concomitant increase in the resources available to programs providing services to individuals with developmental disabilities, unmet needs will have to be addressed through cost-effective management of those resources.
**Economic and social relevance.** The need for research that examines the prevalence and severity of secondary conditions and thus has implications for prevention is evident, as people with disabilities comprise 17% of the U.S. non-institutionalized population, but account for 47% of total medical expenditures (Rice & Trupin, 1996). Based on 1980 National Medical Care Utilization and Expenditure Survey data, LaPlante (1993) estimated that persons with disabilities spent approximately 3.6 times as much on health care as persons without disabilities. Arguably, it is the secondary conditions that may be responsible for a significant proportion of health problems and expenditures for persons with disabilities (Lollar, 1994; Marge, 1988; Pope & Tarlov, 1991).

Furthermore, Pope (1992) asserted that there was a specific need for research on the experience of secondary conditions among persons with developmental disabilities. He cited LaPlante’s (1989) descriptions of the two most common developmental disabilities, mental retardation and cerebral palsy, to highlight the urgency of that need. LaPlante (1989) reported that these two developmental disabilities ranked first and fifth, respectively, among 17 chronic conditions causing major activity limitation in persons of all ages and that they ranked ninth and eighth, respectively, among those same chronic conditions requiring assistance to accomplish daily living activities. The significance of

---

1 In LaPlante’s study (1989), other chronic conditions ranked by percent causing major activity limitation and by percent causing need for help in basic life activities were absence of legs, lung or bronchial cancer, multiple sclerosis, blind in both eyes, partial paralysis in extremity, other orthopedic impairments, complete paralysis in extremity, rheumatoid arthritis, intervertebral disk disorders, paralysis in other sites (complete/partial), other heart disease/disorders, cancer of digestive sites, emphysema, absence of arm(s)/hand(s), and cerebrovascular disease.
such rankings is evident when one considers the costs of delivering supports to reduce activity limitation and provide necessary assistance to persons with developmental disabilities. Prouty and Lakin (2000) estimated that in 1999, 9.9% of total federal Medicaid expenditures (i.e., $10.143 billion) was administered under Title XIX of the Social Security Act to provide active treatment programs (e.g., case management, personal care services, adult day health services, habilitation services, homemaker services, etc.) to persons with mental retardation and related developmental disabilities (MR/DD). Currently, components of these active treatment programs, and hence a percentage of these costs, target acquired and chronic functional limitation associated with significant secondary conditions (e.g., scoliosis, contractures, and communication difficulties; Williams, 1998). Thus, the need for information about the incidence, severity, and etiology of secondary conditions is evident.

**Vulnerability of persons with developmental disabilities.** Overall, there are various cognitive, psychosocial, and biological factors associated with developmental disabilities that may contribute to an increased vulnerability to poor health among adults with developmental disabilities. For example, the hallmark of adults with developmental disabilities receiving services in Montana is mental retardation (i.e., IQ below 70), thus, cognitive impairment may be considered as a vulnerability factor (Eabon, 1987) that increases these individuals' susceptibility to negative outcomes (for a discussion of vulnerability, see Mash & Dazois, 1996 and also Wallace, 1999). Generally, individuals with cognitive impairments generate poorer and fewer coping strategies for handling mild stressors and therefore do not avoid the negative outcomes associated with those stressors.
(e.g., Blackman, Whittemore, Zeitlin, & McNamara, 1977; Moore, 1990). However, cognitive impairments is neither the only, nor the most important, vulnerable characteristic of this population (Zigler & Balla, 1984a; 1984b). A second vulnerable characteristic concerns the increased potential of developing a pessimistic explanatory style given a potentially higher experience of failure among persons with developmental disabilities. A pessimistic explanatory style is characterized by the attribution of negative events to internal (personal) causes as well as stable (permanent) and global (pervasive) implications (Seligman, 1998a). Importantly, having a "pessimistic" explanatory style has been correlated with poor physical and psychosocial health (Seligman, 1998b). Additionally, the opposite may hold true as well. For instance, Scheier et al. (1989) found that optimism was a significant predictor of coping efforts and of recovery from surgery for patients who underwent coronary artery bypasses. Optimists were also more likely to have a higher quality of life six months after surgery than were pessimists.

Although a review of the literature did not reveal specific descriptions of pessimism and optimism among persons with developmental disabilities, there was a general consensus reflected in a statement by Webster (1990): "Individuals who are mentally retarded are likely to experience traumatic rejections, failures, losses, and/or dislocations: the associate reduction in self-esteem further increases their vulnerability" (p. 573). This consensus was largely based on the wealth of research findings regarding learned helplessness present in the developmental disabilities literature (e.g., Blackman et al., 1977; for reviews see Gargiulo and O’Sullivan, 1986; Weisz, 1984). Weisz (1984) summarized: "The passive, resigned orientation displayed by the retarded children
resembled a syndrome that Seligman and his colleagues labeled 'learned helplessness' (Abramson, Seligman, & Teasdale, 1978; Seligman, 1975)" (p. 28). Although future research is needed to elucidate the incidence of pessimism in populations with developmental disabilities, the high incidence of learned helplessness, in conjunction with the more specific descriptions of individuals with mental retardation making internal, stable, and global negative statements about themselves and their abilities, suggest that there may be a high incidence of pessimism among individuals with developmental disabilities relative to populations without early onset disabilities. If so, persons with developmental disabilities may also be more likely to have an increased vulnerability to poor health outcomes.

Finally, biological aspects of developmental disabilities also contribute to the vulnerability of persons within that population. For instance, there is a growing body of literature describing accelerated age-related losses in function among persons with developmental disabilities relative to the rate of age-related losses in the general population (e.g., Hawkins, 1997; Hawkins, Eklund, & Martz, 1992). Additionally, persons with developmental disabilities are more likely to be taking prescribed medication, and to have seizure tendencies, chronic infections, gastrointestinal problems, and poor circulation. These factors, in concert with mild stressors, can result in deleterious effects that are more pronounced relative to populations not experiencing such factors (e.g., Moore, 1990; Seelman & Sweeney, 1995).

To summarize, adults with developmental disabilities are likely to have a pessimistic style of attribution, to have medical profiles defining them as more vulnerable
than adults without mental retardation, and to have fewer and less effective coping strategies when confronted with common stressors (e.g., alcohol or school work). These factors, in addition to low IQ, are important for completing the picture of the vulnerable status of individuals with developmental disabilities. Overall, it is the vulnerability of persons with developmental disabilities, in conjunction with the need to provide cost-effective, health-promoting support services to a growing population, which provided a strong rationale for this study.

Stress

Selye’s (1950) seminal work on stress defined it as a biological reaction to pathological or psychological events. A recent review (Melzack, 1998) details the compelling stress-related research stemming from Selye’s work. In these studies, the stress-regulating systems functioned to restore an organism’s biological homeostasis following some pathology or injury. The goal of the stress reaction is ostensibly to free up glucose so that the organism may adapt appropriately to the situation. The need for increased energy supplies supports Antonovsky’s (1991) notions of stressors as distinct from other stimuli because they are "...a demand made by the internal or external environment of an organism that upsets its homeostasis, restoration of which depends on a nonautomatic and not readily available energy expending action" (p. 72). The extent to which the organism must expend energy to regain homeostasis defines the amount of stress experienced. Thus, the amount of stress experienced varies with the availability of internal and external resources that can reduce the effort expended during adjustment to the stressor.
The main focus of stress studies in the developmental disabilities literature has been on measuring stress experienced by parents and direct care service providers and on assessing associated outcomes, usually in terms of the effects on the system of support (e.g., Dyson, 1997; McCubbin & Patterson, 1983; Razza, 1993; Sharrard, 1992). Similarly, the discussion in the developmental disabilities literature of protective factors for mitigating harmful events due to stress has been limited to those influencing events experienced by parents and caregivers (e.g., Minnes & Nachsen, 1997). Although more research is needed to understand the indirect relationship, a few studies have demonstrated that specific moderators lessening the impact of stress on caregivers also influence the health and behavior of the individual with a disability (e.g., Gottlieb, 1998). Much of this research stems from the conceptualization of primary caregivers as critical components in the health promoting environment of individuals with disabilities (Seekins, Traci, & Szalda-Petree, 1999). The focus on primary caregivers is perhaps appropriate for describing the health promoting environments of children, but for understanding the health promoting environments of adolescents and adults, the scope of research must also include investigations of the stress experienced by the individual with developmental disabilities and investigations of the broad risk and protective factors influencing the relationship between that stress and the individual’s health.

In light of the need for more information in this area, the present study will begin to investigate how stress and health are related in a population of adults with developmental disabilities. In general, these adults have the commonality of mental retardation associated with their primary disability, yet their individual and experiential

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.
differences will inform our understanding of the further disablement resulting from secondary conditions. Pope (1992) suggested that the experiences of stress resulting from disabling conditions (i.e., secondary conditions or primary disabilities) vary among individuals and make unique contributions to processes of disablement among individuals:

"An example of an indirect relation (between primary disability and the disablement process) is a disabling condition that causes new mental/psychological stresses (e.g., uncertainty about the future, changes in living environments and social relationships, and frustration from being unable to gain access to a building) that in turn can cause hypertension or other stress-related diseases" (p. 351).

In the health promotion literature for the general population, objective stressors such as changes in living environment and social relationships are discussed as stressful life events (SLE) or significant life changes (SLC), and conceptually, they contribute to one's mental/psychological stresses. Importantly, SLE's have been shown to be correlated significantly with poor physical and psychological health outcomes (for reviews see, Cohen, 1988; Thoits, 1983). A review of the literature has revealed only one study describing the experience of stressful life events among adults with developmental disabilities (Hawkins et al., 1992). This study described the experience of traditional stressors among older adults with developmental disabilities as being similar to the experience of life events common to most adults. The study did not, however, describe how the experience of life events was related to the health or well-being of these older adults. The present study will test the hypothesis that life events will account for a

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.
significant amount of the variability in the secondary conditions experienced by adults with developmental disabilities.

Secondary Conditions and Prevention

Pope and Tarlov (1991) outlined objectives that would create tertiary prevention strategies for the successful management of primary mobility impairments. In comparison, the objectives for prevention among persons with developmental disabilities were more limited. Specifically, the authors focused on the primary prevention of developmental disabilities that included a review of prevention strategies appropriate to prenatal and early development (e.g., environmental engineering programs such as the lead abatement programs as well as public health education on folic acid supplements and on teratogens like alcohol and stress). Pope's (1992) article, however, acknowledged that despite primary prevention efforts, the population of persons with developmental disabilities is continuing to grow and thus the need for secondary and tertiary prevention strategies for managing developmental disabilities was great. As described above, Pope's article was significant in that it expanded the architecture of the "National Agenda for Prevention" to include the increasing number of persons with developmental disabilities under the framework of secondary conditions.

Although information on secondary conditions experienced by people with developmental disabilities is limited, the literature does contain lists of suggested health practices that might lead to the prevention of some secondary conditions (e.g., Marge, 1988), descriptions of some risk factors such as poor nutrition (Eyman, Chaney, Givens, Lopez, & Lee, 1986), and the identification of various diseases as sources of later limitation.
(Miller & Eyman, 1979). Further, whereas specific secondary conditions are addressed in some of the literature and are part of current programs and services for persons with developmental disabilities; they are not systematically addressed under a unified conceptual framework. For example, although researchers are moving toward such ends (e.g., Traci, Seekins, Szalda-Petree, & Ravesloot, 2000), there are no studies in a defined population of persons with developmental disabilities reporting the incidence, prevalence, or severity of a range of secondary conditions. There are, however, a limited number of empirical studies measuring the effectiveness of various strategies for managing specific secondary conditions among adults with developmental disabilities (for a review, see Frey, Szalda-Petree, Traci, Seekins, & Ravesloot, 2000). This lack of research is unfortunate as information of this type would allow policy makers and program planners to identify the conditions of highest priority for the most people or the low-incidence conditions of the greatest severity and to prevent these conditions with empirically tested and effective strategies. The primary goal of the present study will begin to address this issue by providing empirical information regarding the predictive utility of stressful life events for the experience of secondary conditions among adults with developmental disabilities.

Empirical descriptions of this relationship are needed to make informed decisions about the importance of stress prevention or management strategies in programs of health promotion for this population. Furthermore, the primary goal of the present study provides a general methodology for describing empirical relationships between secondary conditions and other risk factors, and it provides components of methodology necessary for evaluating the effectiveness of programs designed to positively affect such relationships.
Conceptual model for investigating the etiology of secondary conditions. This investigation of secondary conditions was conceptually based, at least in part, on the Institute of Medicine's (IOM) model for preventing secondary conditions (see Figure 1). This model, in conjunction with IOM's model for preventing disability (Pope & Tarlov, 1991, pp. 217 and 85, respectively), presents a dynamic process of disablement that Pope (1992) described as "...central to developing an approach to preventing disability (and secondary conditions)" (p. 347). The description of disability as a dynamic rather than a static entity (Marge, 1988) was at the heart of the paradigm shift in rehabilitation. From this perspective, rehabilitation professionals can now focus on the prevention of secondary conditions to which persons with primary disabling conditions have lifelong vulnerability, as opposed to focusing solely on prevention of the primary condition.

In addition, central to both models is the notion that the process of disablement may affect individuals multidirectionally through levels of pathology, impairment, functional limitation, and disability; the corresponding levels of reference are "cells and tissue; organs and organ systems; organism- action or activity performance (consistent with the purpose or function of the organ or organ system); and society- task performance within the social and cultural context" (Pope & Tarlov, 1991, p. 79). The suggested factors furthering an individual's engagement in the process of disablement for secondary conditions include biological, environmental (physical and social), lifestyle or behavioral factors and primary disabling conditions. Within the IOM model of secondary conditions, these are represented as a nexus of risk factors preceding and within the disabling process for secondary conditions, suggesting that they may directly or indirectly contribute to the
onset of secondary pathology and to the further engagement in the process of secondary disablement (i.e., onset of secondary impairment, secondary functional limitation, or secondary disability).

Figure 1. The Institute of Medicine model for secondary conditions (Pope & Tarlov, 1991, p. 217): Influence of risk factors and life events on the disabling process for secondary conditions and quality of life.
Given the IOM model for secondary conditions, life changes could conceivably influence, either directly or indirectly, the occurrence of a new secondary pathology or could influence the progression of a secondary condition towards limitation and disability within the process of disablement for a secondary condition. Disruption in normal care of the individual, change in personal care attendant, pregnancy, and change in medication are examples of life changes that could contribute directly to the experience of new secondary conditions such as personal hygiene and appearance problems, gastrointestinal dysfunction, and side effects of medication. Changes in working conditions, residence, transportation, and recreation are life changes that could contribute indirectly to the experience of a new secondary condition. For instance, changes in working conditions could prohibit an individual from maintaining a bowel management program, which in turn could result in painful bowel impaction. Because the progression of a secondary condition within the disabling process could occur as a result of a number of life changes, it will be important to consider how potential moderators will interact with life changes.

Health, Risk and Protective Factors

The present study investigated whether the deleterious effects of life events on health described for populations without mental retardation could also be found in a sample of adults with developmental disabilities. The following review of current conceptualizations from the domains of child psychopathology and lifespan development provided a theoretical framework for the exploratory investigations of personal and environmental characteristics’ influences on the experience of life changes and secondary conditions. Essentially, the review of resiliency, reserve capacity, and plasticity highlights...
the importance of individual variability in the explanation of human development.

Staudinger, Marsiske, and Baltes (1993) propose plasticity as an index of how flexible and robust an individual is in dealing with challenges and demands. A person’s degree of plasticity also predicts whether her balance of developmental gains to losses across varying domains of human development will increase, decrease, or remain the same (Staudinger et al., 1993) and whether she will adapt positively or negatively to developmental challenges (Staudinger et al., 1995). A person’s resilience, reserve capacity, and vulnerability, concepts from the fields of developmental psychopathology and lifespan development, are factors influencing the multidirectional nature of human plasticity.

The term resilience has not been uniformly defined within the field of developmental psychopathology (for a review, see Kaplan, 1999). Various investigations of resilience have operationalized it as being a personal attribute allowing individuals: 1) to endure stress while maintaining developmental competencies; 2) to experience traumatic events and thereafter, recover developmental competencies; and 3) to be at significant risk for the development of psychopathology yet avoid that negative outcome and/or to make developmental gains despite such risk (Mash & Dozois, 1996). Lifespan developmentalists limit their usage of resiliency to the first two definitions and designate the term, reserve capacity for describing an individual’s potential for change and for movement beyond previous levels of functioning (Staudinger et al., 1995). Resiliency and reserve capacity each can be thought of as types of plasticity predicting positive adaptation in the face of challenge. Resiliency is associated with a maintained balance of developmental gains to losses, whereas reserve capacity is associated with either a maintained or an increased...
balance of developmental gains to losses. Vulnerability, a concept from developmental psychopathology, can be conceptualized as the counterpart to resiliency (e.g., Wallace, 1999). Within the framework of lifespan developmental theory, vulnerability may be considered to be another type of plasticity, one that is associated with overall negative adaptation, a decrease in the balance of developmental gains to losses, and a loss of the resources that contribute to reserve capacity.

In the field of developmental psychopathology, risk and protective factors are described by studies investigating the personal and environmental attributes of resilient and vulnerable individuals (Mash & Dozois, 1996). One could consider risk and protective factors to be resources that contribute to a person's reserve capacity, either negatively or positively (Staudinger et al., 1993). Together these resources influence the course of human development, although this influence does not occur in a unidirectional or unidimensional pattern. The present study was considered from the broad lifespan perspective that views human development as emergent from "...dynamic and probabilistic transactions among diverse sources of developmental influences and selection processes" (Staudinger et al., 1995, p. 807). As Cicchetti and Toth (1998) illustrate in their ecological transactional model of the etiologies of childhood depression, understanding resiliency requires the examination of potentiating and compensatory risk factors (i.e, risk and protective factors) and the interactions of those factors within the individual and her ecology. An example germane to a population with developmental disabilities involves the risk factors of chronic poverty, familial stress, and sensory impairment. The interaction of those factors was illustrated in the biography of a male student at the Lexington School
for the Deaf (Cohen, 1994). This young man’s mother was a single parent of five children. His family was extremely poor, yet was not accessing the social supports available through government programs. Two of his siblings also had disabilities (spina bifida and conduct disorder). Together, these issues resulted in high levels of familial stress. The etiologies of many childhood psychopathologies involve chronic poverty, familial stress, and a lack of supports. In the case of his siblings, these factors acted as potentiating risk factors that resulted in various negative outcomes, including dropping out of high-school, teenage pregnancy, anti-social personality disorder and incarceration, as well as isolation and depression. In the case of the young man, these factors interacted with his deafness, qualifying him for extra social supports provided in the established education systems for the Deaf in New York City. These supports may have contributed to the lack of psychopathology and adolescent problems in his later development, and to the positive outcomes of high school graduation and acceptance to college. Consequently, the deafness and associated social supports acted as compensatory risk factors for this young man.

Understanding pathways to health and well-being among individuals with lifelong disability is advanced by the application of concepts such as resiliency and reserve capacity. Secondary conditions are experienced differently among persons with developmental disabilities, which suggests variation in the availability and types of protective factors modifying their responses to common environmental stressors such as life changes. Overall, the present study included an investigation of the compensatory and transactional nature of several characteristics and attributes (e.g., age, gender, residential living arrangement, level of disability severity, number of individual plans related to
secondary conditions, and county of residence’s urban-rural classification) for the experience of secondary conditions. These exploratory analyses are discussed in more detail below.

**Exploratory Analyses**

In the life events literature, correlations between life events and poor health outcomes are significant but low (e.g., $r = .20$ or $ .30$), accounting for a small percentage of the variance seen in health (Thoits, 1983). The consistency of such findings provides support for the existence of buffers that lessen the deleterious effects of life changes on health. These include enduring personal attributes (e.g., physiology, personality traits, and psychological consequences of life experiences) and perhaps more transient environmental and psychosocial resources such as available social support and coping strategies (Thoits, 1983). The present exploratory analyses were composed of investigations of how potential protective attributes combine to produce secondary conditions limiting the participation of consumers and how the same attributes combine to produce functional limitation severity associated with secondary conditions.

Personal attributes examined in the present study included age, gender, and severity level of disability. Environmental and psychosocial resources (i.e., type of living arrangement, number of individual plans addressing specific secondary conditions, and county of residence’s urban-rural classification) were also investigated. The exploratory analyses sought to identify levels of life change and important attributes and resources that defined profiles of individuals and contributed to pathways leading to different outcomes. It is important to emphasize that profiles and pathways do not specify the underlying
mechanisms by which more optimal outcomes result given combinations of personal and environmental attributes. For example, Keenan and Shaw (1997) observed that gender may be a risk factor for specific types of problem behaviors (e.g., internalizing disorders for girls and externalizing disorders for boys), but the developmental trajectories towards specific types of psychopathology result from specific behaviors and environmental factors related to gender. That is, relationships demonstrating the predictive utility of gender can inform future investigations of the internally valid causal factors of psychopathology by suggesting closer examination of influential factors (e.g., social and biological resources) embedded in the developmental trajectories delineated by gender. In a similar manner, the present study attempted to identify factors that define profiles of groups of individuals who differ in their experiences of secondary conditions. Future investigations of the underlying mechanisms important to health promotion among adults with developmental disabilities can then explore the psychosocial, biological and environmental factors varying among these groups of individuals characterized by general personal attributes and environmental characteristics.

Using the IOM model for secondary conditions (Figure 1), the personal and environmental factors of interest in the present study can be considered as contributing additively or interactively to the experience of secondary conditions. Age is of interest as a risk factor preceding the disabling process and as a risk factor contributing to the progression of secondary conditions within the process. Hawkins et al. (1992) have described the life changes associated with older adults with mental retardation, and many of those changes involved loss of personal function and loss of social acquaintances. These
age-related changes could initiate a form of pathology (e.g., depression) or could influence
a secondary functional limitation to become a secondary disability (e.g., the loss of a
parent could move an individual into a community setting in which her abilities differ from
societal norms). Living arrangement, number of individual plans addressing specific
secondary conditions, and county of residence's urban-rural classification were chosen as
variables for inclusion because they reflect varying levels of formal and informal social
support as well as varying mechanisms through which health care and health promotion
information may be accessed (Minnes et al., 1989; Prouty & Lakin, 2000). Level of
disability severity was also explored in these analyses. Because eligibility for adult DDP
was determined for the majority of participating consumers by the presence of mental
retardation, level of disability provided an index, at least in part, of the cognitive abilities
of individuals in the sample. Testing for an interaction between level of disability and those
factors reflecting levels of social support was of great interest in light of the observations
of early focus groups involved in the project. A resulting consensus of these groups
suggested that persons with moderate disabilities who were being moved into more
independent settings (i.e. less formal support) would be at greater risk for developing
health problems relative to individuals with high levels of disability severity maintaining
high levels of support in ICF-MRs or intensive care group homes and relative to persons
with low levels of disability severity living independently with relatively little support.

As stated above, the influence of a life change or stressor on health is moderated by
the amount of quality social support and cognitive ability (Thoits, 1983). Thus, the
personal and environmental factors of interest to the present study were included in the
exploratory analyses to discern if they additively or interactively resulted in decreased experience of secondary conditions. For example, a change in the eating habits of an individual residing in a group home may have been observed and evaluated earlier than a similar change occurring for a person in a supported living arrangement. In the IOM model, early detection could prevent the pathologies of weight gain and muscle loss. Also, direct observation and feedback could have prevented gastrointestinal dysfunction or bowel dysfunction, secondary conditions which can develop from pathological swallowing and abdominal musculatures that poorly process certain foods. In another situation, an individual may have experienced a change in transportation that disallowed her attending a community-based aerobics class. Informal social support may have created new transportation that allowed this individual to continue class participation. In most cases, maintained exercise can prevent the onset of secondary conditions such as depression and physical fitness and conditioning problems (for a review, see Anderson, 1993). For persons with cerebral palsy, whose lung capacity and muscle tone is typically observed to be functionally diminished and low, continued cardiovascular activity could prevent secondary conditions such as respiratory problems and balance problems. Again, investigations beyond the present study will be necessary to describe the specific underlying mechanisms that moderate the relationship between life change and the experience of secondary conditions. However, the personal and environmental attributes of interest in the present study were selected because measures of traditional moderators (i.e., social support and cognitive ability) are expected to vary with dimensions or indices of these attributes.
**Exploratory Hypotheses**

The present study investigated the predictive utility of the number of stressful life changes for understanding the experience of secondary conditions in a sample of adults with developmental disabilities. Additionally, the present study tested general exploratory hypotheses concerning the effects of various personal and environmental factors on the experience of secondary conditions. It was hypothesized that these effects could be either cumulative or compensatory in nature. To test these exploratory hypotheses, the present study utilized a relatively new statistical technology called Classification and Regression Tree analyses (Breiman, Friedman, Oshen, & Stone, 1984), which is commonly referred to as CART. CART offers a binary recursive partitioning, nonparametric alternative to multiple regression (Serocynski, Cole, & Maxwell, 1997) for the exploration of the nonlinear relationships of potential predictors and the interactions of those predictors (see data analysis description for more detail about CART). A unique outcome of the procedure is a decision tree. Strengths of CART include its ability to describe complex, nonlinear relationships as well as complex interaction patterns (e.g., Wallace, Bergeman, & Maxwell, 2000) and its portrayal of these interactions in easily interpretable decision trees, which facilitate the use of empirical findings in clinical practices more than regression models and associated $\beta$ weights (e.g., Lemsky, Smith, Malec, & Ivnik, 1996).

CART divides participants into nodes or subgroups of individuals at higher risk for experiencing more secondary conditions or more functional limitation due to secondary conditions, or who were protected in some way from such experiences. Additionally, CART allows for the exploration of cumulative effects, either positive or negative, and
compensatory effects, either positive or negative. Positive cumulation occurs when beneficial effects of multiple factors compile in an additive fashion resulting in increased gains, whereas negative cumulation occurs when the absence of multiple factors generates additive gains in terms of poor outcomes. In addition to cumulative effects, potential compensatory effects were also investigated. For instance, positive compensatory effects occur when the poor outcomes associated with a specific factor were avoided given the presence of another factor, whereas negative compensatory effects involve the negative effect of one factor dampening the beneficial effect of another. Given the exploratory nature of these analyses, the above broad-based hypotheses were proposed without specifying that any particular variable would behave in a certain manner. It was expected, however, that the number of life events would be a salient predictor and would contribute to both cumulative and compensatory effects.

Method

Participants

The present study used data collected as part of health surveillance activities of adult consumers of services provided by the Montana State Department of Health and Human Services Developmental Disabilities Program (DHHSDDP). Information was collected from a pilot sample of 266 adults. These data were collected in three waves of pilot work. All participants were volunteers and were recruited from private service corporations contracting with the state of Montana to provide community-based services and from a state ICF-MR. Directors of service agencies were asked to recruit equal numbers of men and women and equal numbers of persons they considered to be relatively healthy and unhealthy. During the first wave of data collection, surveys were completed
for 29 individuals by direct care service providers familiar with the participating individuals, and eleven of the 29 also had a second survey completed for them by case managers for the purpose of calculating inter-rater reliability estimates for the surveillance instrument. During the second and third waves, surveys were completed for 96 individuals and 156 individuals, respectively. During the first wave, participants were recruited only from Western Montana, whereas during the second and third waves, participants were recruited from Western and Eastern Montana. These data were collected over a period of 18 months (October, 1997-May, 1998). Two individuals from the third wave withdrew from the study and their data were not included in the analyses. Thirteen individuals participated in more than one wave of data collection; only their most recent data were included in the present study.

Individuals ranged in age from 17 to 84 (M = 43.78; SD=13.36). There were approximately equal numbers of men and women (52.1% and 47.9%, respectively). About three quarters (72%) of the participants lived in remote-rural counties (i.e., non-metropolitan counties non-adjacent to a nearby metropolitan county), whereas the remaining quarter (28%) lived in urban counties (i.e., metropolitan counties with at least a 100,000 population size), as defined by USDA Urban-Rural continuum code or "Beale code" (McGranahan, Hession, Hines, & Jordan, 1986). No participants were living in semi-rural counties (i.e., non-metropolitan counties economically adjacent to metropolitan county, which implies that non-metropolitan county residents commute to a nearby metropolitan county) in Montana. Thirty-four (12.9%) individuals lived in either an independent residence or with a family (adopted or natural); 87% were in supported living arrangements (i.e., supported independent living arrangement, intensive care group home,
non-intensive group home, or ICF-MR). See Table 1 for a further description of the sample characteristics.

Inventory for Client and Agency Planning (ICAP; Bruinicks, Hill, Weatherman, & Woodcock, 1986) data, which are collected annually for persons served by the Montana DDP, were available for a subset of participants (N = 147). Mental retardation was indicated as the primary disability for the majority of the subsample (88.5%) and as an additional diagnosis for a small percentage of the subsample (4.5%). Cerebral palsy was indicated as the primary disability without an additional diagnosis for one participant (i.e., having no diagnosis of mental retardation). The ICAP asks raters to indicate the levels of mental retardation as: not mentally retarded (IQ > 70), mild (IQ 52-70), moderate (IQ 36-51), severe (IQ 20-35), profound (IQ under 20), or unknown. The subsample was distributed among those five levels of mental retardation as follows: 0.7%, 35.4%, 36.7%, 12.9%, 12.9%, and 1.4%. Using ICAP data available for adult consumers of Montana DPHHSDDP (as of January 15, 1998), population descriptors were estimated. Comparatively, the present sample was representative of consumers of state developmental disability adult service programs in terms of age, gender, and primary disability.

For the present study, the acceptable risk of Type I error (i.e., α) was .05. In order to minimize the probability of Type II errors (i.e., β ≤ .20) in multiple regressions with three predictors, the number of participants (N = 266) in the present study exceeded the sample size required for sufficient power (.80) to detect a medium effect size (ES; i.e., $f^2 = .15, R^2 = .1304$), but fell short of the sample size required to detect a small effect size (i.e., $f^2 = .02, R^2 = .0196$) (Cohen, 1992; for more details on the power analyses performed for this study, see Appendix B).
Table 1

Sample characteristics: Age and Sum of Individual Plans Addressing Secondary Conditions

By Gender, Level of Disability Severity, Living Arrangement, and County of Residence's Urban-Rural Classification

<table>
<thead>
<tr>
<th>Variables</th>
<th>N</th>
<th>%</th>
<th>M</th>
<th>SD</th>
<th>Range</th>
<th>M</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>139</td>
<td>52.9</td>
<td>42.71</td>
<td>12.89</td>
<td>18-81</td>
<td>3.68</td>
<td>4.19</td>
<td>0-18</td>
</tr>
<tr>
<td>Women</td>
<td>124</td>
<td>47.1</td>
<td>45.10</td>
<td>14.00</td>
<td>17-84</td>
<td>3.60</td>
<td>4.28</td>
<td>0-24</td>
</tr>
<tr>
<td><strong>Disability Severity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>80</td>
<td>31.3</td>
<td>43.34</td>
<td>11.76</td>
<td>21-82</td>
<td>2.64</td>
<td>3.46</td>
<td>0-19</td>
</tr>
<tr>
<td>Moderate</td>
<td>92</td>
<td>35.9</td>
<td>45.43</td>
<td>14.16</td>
<td>23-82</td>
<td>3.84</td>
<td>4.44</td>
<td>0-24</td>
</tr>
<tr>
<td>Severe</td>
<td>84</td>
<td>32.8</td>
<td>42.86</td>
<td>13.59</td>
<td>17-84</td>
<td>4.27</td>
<td>4.58</td>
<td>0-18</td>
</tr>
<tr>
<td><strong>Living Arrangement</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Independent Res.</td>
<td>16</td>
<td>6.0</td>
<td>40.93</td>
<td>10.05</td>
<td>21-52</td>
<td>1.94</td>
<td>2.72</td>
<td>0-9</td>
</tr>
<tr>
<td>Supported Living</td>
<td>46</td>
<td>18.0</td>
<td>42.48</td>
<td>12.27</td>
<td>21-84</td>
<td>2.96</td>
<td>2.90</td>
<td>0-12</td>
</tr>
<tr>
<td>Family/Foster Home</td>
<td>18</td>
<td>6.8</td>
<td>35.00</td>
<td>12.40</td>
<td>23-60</td>
<td>1.61</td>
<td>2.17</td>
<td>0-6</td>
</tr>
<tr>
<td>Group Home (GH)</td>
<td>122</td>
<td>45.9</td>
<td>47.16</td>
<td>14.36</td>
<td>17-82</td>
<td>3.61</td>
<td>4.65</td>
<td>0-24</td>
</tr>
<tr>
<td>Intensive GH</td>
<td>58</td>
<td>21.8</td>
<td>41.13</td>
<td>11.71</td>
<td>24-78</td>
<td>4.57</td>
<td>4.33</td>
<td>0-18</td>
</tr>
<tr>
<td>Institutional Setting</td>
<td>6</td>
<td>1.5</td>
<td>43.80</td>
<td>10.11</td>
<td>30-58</td>
<td>8.50</td>
<td>5.09</td>
<td>0-13</td>
</tr>
<tr>
<td><strong>County of Residence</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>179</td>
<td>67.3</td>
<td>43.75</td>
<td>14.19</td>
<td>21-84</td>
<td>3.82</td>
<td>4.38</td>
<td>0-24</td>
</tr>
<tr>
<td>Rural</td>
<td>87</td>
<td>32.7</td>
<td>43.85</td>
<td>11.62</td>
<td>17-75</td>
<td>3.16</td>
<td>3.85</td>
<td>0-15</td>
</tr>
<tr>
<td>Sample</td>
<td>266</td>
<td>100</td>
<td>43.78</td>
<td>13.36</td>
<td>17-84</td>
<td>3.60</td>
<td>4.22</td>
<td>0-24</td>
</tr>
</tbody>
</table>

Note. aIndividual Plans (IPs) objectives addressing secondary conditions; btwo cases had missing data; cten cases had missing data; dIndependent residence or living arrangement; eGroup Home; fIntermediate care facility (ICF-MR) or nursing home.
Measures

The development of the Health and Secondary Conditions Surveillance Instrument for Adults with Developmental Disabilities (HSCSIADD, see Appendix C) and its procedures involved principles of Participatory Action Research (PAR; Whyte, 1991), which calls for a dynamic interplay between researchers and potential adopters who help define research goals, develop acceptable procedures, and judge the significance of research products (Seekins, Mathews, Fawcett, Jones, & Budde, 1988). Because direct care providers were designated by the project’s advisory panel as the primary raters and because consumers were to be auxiliary to the survey completion process, current data collection falls more clearly under the rubric of Constituency-Oriented Research and Dissemination (Fenton, Batavia, & Roody, 1993), which allows for family members and service providers to act as primary constituents. In contrast, PAR’s more stringent philosophy would require consumers to be the primary raters. The HSCSIADD included an assessment of secondary conditions, life events, demographic information, overall health and independence, and an 8-item health care-utilization and accessibility measure.

Secondary Conditions. The secondary conditions surveillance instrument (Ravesloot, Seekins, & Walsh, 1997; Ravesloot, Seekins, & Young, 1998; Seekins et al., 1999; Seekins, Clay, & Ravesloot, 1994; Seekins, 1992; Traci et al., 2000; Szalda-Petree, Traci, Seekins, & Ravesloot, 2000) included an assessment of the number of secondary conditions limiting the participation of consumers and assessment of the amount of functional limitation associated with each of the 44 possible secondary conditions. Functional limitation was measured using a 4-point Likert scale ranging from zero (no
limitation) to three (significant/chronic limitation of activities; limits activity 1-10 hours per week). Ratings on the assessment of functional limitation due to secondary conditions reflect restrictions in activities during the past year. To ease completion of the instrument and to emphasize that medical treatment is essential for a subset of conditions, secondary condition items are presented in three sections: Observed secondary conditions (e.g. weight problems, bowel dysfunction, persistence problems/low frustration tolerance); Possible or identified medical secondary conditions (e.g. gastrointestinal dysfunction, side effects from medications, urinary tract infections); and secondary conditions related to mobility impairment (e.g., pressure sores, equipment-related injuries to consumer, injuries due to loss of sensation). Participating direct care providers rated secondary conditions in the third section only if mobility impairment was a concern for the consumer. The summary scores for the assessment used in this study were the frequency of secondary conditions limiting the participation of consumers and the sum of functional limitation severity ratings associated with the secondary conditions. High scores on frequency of secondary conditions and on the sum of functional limitation severity ratings indicated more health conditions requiring treatment or prevention programs and increased limitation associated with health conditions, respectively. Summary scores reflect completion criteria of 80% (i.e., descriptors for cases with less than 20% missing data). Four cases did not meet this criteria. In the present study, internal consistency reliability for the sum of severity ratings was acceptable, with Cronbach’s alpha equal to .87; this estimate presumably reflects sufficient sampling of the domain of interest, in this case, limitation in daily living activities due to health.
Eleven pairs of respondents provided data for the calculation of inter-rater reliability for the instrument; pairs included a direct care provider and a case manager. Members of each pair independently completed surveys for the same consumer so that the health of 11 consumers was provided twice, once by a direct care provider and once by a case manager. The chance-corrected measurement of agreement for data contributing to the summary score of frequency of secondary conditions was moderate ($\kappa = .41$). This kappa was calculated to reflect how frequency of secondary conditions has traditionally been calculated by researchers using the secondary conditions surveillance instrument for persons with mobility impairments and the instrument for persons with developmental disabilities. In this case, an estimation of no limitation (i.e., zero) for a condition by both raters was counted as an agreement. Additionally, an estimation of some amount of limitation (mild, moderate, or significant; i.e, 1, 2, or 3) by both raters was counted as an agreement. The definition of a disagreement was met when one rater indicated that no limitation was associated with a secondary condition and the other rater indicated that some amount of limitation was associated with the same condition. A conservative Cohen’s kappa for the severity ratings of all secondary conditions (i.e., 44 secondary conditions) was fair ($\kappa = .32$). A weighted kappa, in which greater weights were assigned incrementally to off-diagonal disagreements, was moderate ($\kappa_w = .48$; for a more detailed description of the reliability of these dependent measures, see Appendix D).

Stress and Life Changes Inventory. Again using principles of PAR, the Life Changes Inventory for Adults with Developmental Disabilities (LCIADD) was adopted from Holmes and Rahe’s (1967) Social Readjustment Rating Scale (SRRS). The
inventory, which includes 37 life changes identified by primary constituents as significant for adults with developmental disabilities, referred to life changes experienced during the past two years. The SRRS items concerning marriage, spouses or mates, friends, and children were either dropped or revised using persons consistently present in the daily living environments of adults with developmental disabilities (e.g., personal care attendant, case manager, roommate or housemate). In addition, the SRRS item, pregnancy, was retained on the inventory whereas Christmas was not. Finally, change in transportation (including a bus route or van schedule) was added to the inventory. The data provided by the eleven pairs of respondents was also used to calculate inter-rater reliability for the stress inventory. As described above, pairs included a direct care provider and a case manager, and the members of each pair independently completed inventories for the same consumer. As a result, the life changes experienced by 11 consumers were identified twice, once by a direct care provider and once by a case manager. The corrected chance agreement for this inventory was moderate ($\kappa = .41$).

**Demographics.** The demographic variables of the present study include age, gender, type of living arrangement, level of disability severity, number of individual plan (IP) objectives addressing secondary conditions, and county of residence’s urban-rural classification. Age was reported for each participant in terms of years. Raters indicated in what type of living arrangement the consumers resided: independent residence, family home, supported living arrangement, intensive care group home, non-intensive group home, institution (ICF-MRs or nursing homes), or foster home/host family. These residences were grouped into five nominal categories: 1) independent residence, 2) family,
foster/host family residences; 3) supported living arrangement; 4) non-intensive group home; 5) intensive care group home, ICF-MR, and nursing home. Raters estimated the approximate level of disability severity for the participating consumers by checking the appropriate increment from a three-point scale: mild, moderate, or severe. Finally, the presence or absence of an IP objective targeting a secondary condition was indicated for each secondary condition item.

**Data Analysis.** To accomplish the primary goal of the present study, two ordinary least squares regression analyses were conducted with the criterion variables, frequencies of secondary conditions experienced as limiting (SC\text{frequency}) and the sum of severity limitation ratings associated with secondary conditions (SC\text{severity}). These variables were regressed onto life changes controlling for important demographic conditions.

CART was used to test the general exploratory hypotheses of the present study. This statistical technology produces decision trees that map results and illustrate cumulative and compensatory effects where present. To arrive at reliable and valid decision trees, CART proceeds through a standard sequence of analyses. To illustrate the steps used by CART to generate a decision tree, an artificial example tree was created using frequency of secondary conditions experienced as limiting as the dependent variable (see Figure 2). Initially, CART generates a root node, or a group, that contains the entire sample. CART then examines all possible predictor variables (note that the predictors examined by CART may be of nominal, ordinal, interval, or ratio scales) to identify the optimal predictor by which the root node may be split into
subgroups (i.e., child nodes 2 and 3). The optimal predictor variable provides a cut-off point for classifying individuals into subgroups that minimize the within-group variance in the dependent measure. Unlike regression, the selection of the optimal predictor is done with replacement (e.g., Predictor A is selected twice as an optimal predictor in Figure 2). The optimality principle is then used to identify the optimal predictor variables and cut-off points specific to nodes 2 and 3 (e.g., Predictors B and C in Figure 2). Nodes 2 and 3 are then split into nodes 4 and 5 and nodes 6 and 7, respectively. The growth of the tree continues recursively until the terminal nodes are generated, that is, until no further splits in the sample can be made. A tree with a maximal numbers of branches results; CART then prunes backwards by examining a series of smaller trees in order to exclude branches that capitalize on sampling error or chance. Importantly, a maximal tree allows for the inclusion of potentially important branches, whereas the pruning procedure ensures that the tree does not capitalize on chance. In order to retain all important branches that are generalizable beyond the sample during the pruning procedure, CART withdraws holdout samples (e.g. 10% of the sample referred to as the test samples) from the original sample (referred to as the learning sample) to cross- validate the model. Cross-validation specifically involves the examination of estimates of the error rates of selected sub-trees. Data from the holdout samples are used to reliably estimate the independent predictive accuracy of smaller versions of the maximal tree generated from the pruning of branches and resulting in various numbers of terminal nodes.
Figure 2. Artificial example of classification and regression tree diagram for heuristic purposes only. The frequency of secondary conditions experienced as limiting is the dependent measure suggested in this tree. Note that continuous independent and dependent measures have been standardized.
CART is able to illustrate positive and negative cumulative effects and positive and negative compensatory effects in the decisions trees. For example, a female individual having experienced fewer stressful life events and severity associated with her overall disability would be experiencing a positive cumulative effect in terms of a reduced frequency of secondary conditions. (In Figure 2, the positive cumulative effect would result in a frequency of secondary conditions 1.7 standard deviations below the mean; see pathway connected by nodes 1, 3, 7, and 15). For negative cumulative effects, one would expect the absences of protective attributes to have increasingly poor results. For example, in a group experiencing a potentiating number of life changes, group members without informal supports (e.g., resident of urban county) and without formal supports (e.g., resident of independent living arrangements) would be expected to experience secondary conditions as limiting. (In Figure 2, the negative cumulative effect would result in a frequency of secondary conditions 1.7 standard deviations above the mean; see pathway connected by nodes 1, 2, 4, and 8). In regards to positive compensatory effects, the negative effects associated with a factor can be buffered by the beneficial effects of another protective attribute. For instance, in a group experiencing relatively few life changes, members experiencing a potentiating level of overall disability severity yet having a given number of health-related IP objectives might experience few secondary conditions as limiting. (In Figure 2, the positive compensatory effect would result in a frequency of secondary conditions 0.4 standard deviations below the mean; see pathway connected by nodes 1, 3, 6, and 13). The pattern of negative compensation involves the annulment of
the beneficial effects of a factor by the detrimental effects of another factor. In terms of the experience of secondary conditions, the beneficial effects of experiencing few changes would be circumvented by the negative contributions of a high level of overall disability severity and a small number of health-related IP objectives. (In Figure 2, the negative compensatory effect would result in a frequency of secondary conditions 0.9 standard deviations above the mean; see pathway connected by nodes 1, 3, 6, and 12). Although this is a hypothetical example, the trees included in the present study may be interpreted in a similar way.

Results

Descriptive Statistics

Descriptive statistics, including means and standard deviations by gender and correlations of the dependent variables with age can be found in Table 2. Student t-ratios revealed no significant variation between genders on the measures of frequency of secondary conditions and sum of severity ratings associated with secondary conditions. Correlation analyses revealed that age was significantly related to the frequency of secondary conditions and to the sum of severity ratings. These low to moderate correlations suggested that as age increased, there was a related increase in the frequency of secondary conditions experienced by consumers and in the sum of severity ratings of limitation associated with secondary conditions. Given these findings, age, but not gender, were controlled for in the regression analyses testing the relationships between life changes and the experience of secondary conditions. Other traditional demographic variables such as SES and level of education were not available in the current data set.
Table 2
Means and Standard Deviations by Gender and Correlations Between Age, Frequency of Secondary Conditions, and Sum of Severity Ratings Associated with Secondary Conditions.

<table>
<thead>
<tr>
<th>Measure</th>
<th>M</th>
<th>SD</th>
<th>M</th>
<th>SD</th>
<th>( r_{age} )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequency of Secondary Conditions</td>
<td>9.51</td>
<td>5.86</td>
<td>10.19</td>
<td>6.68</td>
<td>.25***</td>
</tr>
<tr>
<td>Sum of Severity Ratings</td>
<td>15.25</td>
<td>11.81</td>
<td>16.07</td>
<td>12.20</td>
<td>.20***</td>
</tr>
</tbody>
</table>

Note. \( *= \) Pearson product-moment correlation coefficients, which were tested for significance using a two-tailed approach (\( N = 260-266 \); *** \( p < .001 \).

Life Changes and the Experience of Secondary Conditions

To test the hypothesis that there is a significant and positive, linear relationship between scores on the LCIADD (TOT LC) and the frequency of secondary conditions experienced as limiting (SC\(_{frequency}\)), SC\(_{frequency}\) was regressed onto life changes and age. To test the hypothesis asserting that there is a linear relationship between TOT LC and the sum of severity limitation ratings associated with secondary conditions (SC\(_{severity}\)), SC\(_{severity}\) was regressed onto the TOT LC and age. From the univariate and multivariate perspectives, data were homoscedastic and analyses did not have to address issues of multicollinearity or curvilinearity. No outliers were identified as the distributions of each variable were considered to be representative of the population. Nonnormal, positively
skewed distributions for the two independent and the two dependent variables were indicated, however. Therefore, remedies to address the assumption of normality (i.e., appropriate transformations) were applied to the data sets. Because the applied transformations rendered the findings less interpretable, the resulting regression models were compared to models derived from the nontransformed data. Given the similarity in the patterns of results from regressions analyzing the transformed and nontransformed data, only the interpretations of the models derived from the nontransformed data are discussed further (see Appendix E for details concerning the univariate and multivariate examinations of the assumptions of multiple regression and for a description of models derived from the transformed data).

Initial correlation analyses of the individual variables revealed that the relationships between the TOT LC and the SC_freq (r = .12, p = .06) and between the TOT LC and the SC_severity (r = .11, p = .07) were not significant. However, trends toward significance in these correlations, in conjunction with the numerous findings regarding such relationships in other populations, lend precedence toward the examination of those relationships with multiple regression. Both relationships showed positive trends indicating that more life changes were associated with the experience of more secondary conditions and with greater sums of severity ratings associated with secondary conditions. This information will aid in the interpretation of the variates (below). Furthermore, relevant indices from the regression models convincingly indicated that the unique variance of the total number of life changes was not being suppressed or masked by shared variance with age; the tolerance values and variance inflation factors (VIF), as well as the condition
indices indicated that beta coefficients could be interpreted directly. To summarize, multicollinearity did not seem to be an issue to consider when interpreting these models. Finally, the residuals from each regression model were plotted against life changes and against age data. None of these plots revealed variation of the error terms across predictor values. Hence, the further examination of curvilinear effects was not necessary.

Table 3 describes the regression models that, using age and TOT LC as independent variables, predicted: (Model 1) the frequency of secondary conditions experienced by consumers of state DDP (SC_{frequency} = b_o + b_1(Age) + b_2(TOT LC) + \epsilon) and (Model 2) the sum of severity ratings associated with secondary conditions experienced by consumers of state DDP (SC_{severity} = b_o + b_1(Age) + b_2(TOT LC) + \epsilon).

For Model 1 (R^2 = .08, F(2, 254) = 10.45, p < .05), age was a significant predictor of SC_{frequency} (b_1 = .12, \beta_1 = .26, t(255) = 4.27, p < .05). In Model 1, age uniquely accounted for 6.7% of the variance in the criterion variable, frequency of secondary conditions. Model 1 predicts that an increase in age of one year is related to an increase of .12 units in the frequency of secondary conditions. For 95% of the sample, an increase in age of one year is related to an increase in units of the frequency of secondary conditions ranging from .07 to .18. In Model 1, total life changes was a significant predictor of SC_{frequency} (b_2 = .18, \beta_2 = .13; t(255) = 2.08, p < .05). It uniquely accounted for 1.6% of the variance in the SC_{frequency}. From Model 1, one may surmise that one unit change in life change predicts a .18 unit change in SC_{frequency}. Taking into account the confidence interval (CI), one may predict that with one unit increase in life change, 95% of the sample will experience an increase ranging from .01 to .36 units in the frequency of secondary
### Table 3

**Summary of Regression Analyses Predicting the Frequency of Secondary Conditions and the Sum of Severity Ratings Associated with Secondary Conditions of Consumers of Montana DDP.**

<table>
<thead>
<tr>
<th>Variable</th>
<th>$R^2$</th>
<th>$F (2, 254)$</th>
<th>$B$</th>
<th>SE $B$</th>
<th>$\beta$</th>
<th>$t (255)$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Model 1 (Predicting SC$_{frequency}$)</strong></td>
<td>.08</td>
<td>10.45***</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consumer's Age</td>
<td></td>
<td></td>
<td>.12</td>
<td>.03</td>
<td>.26</td>
<td>4.27***</td>
</tr>
<tr>
<td>Total Life Changes</td>
<td></td>
<td></td>
<td>.18</td>
<td>.09</td>
<td>.13</td>
<td>2.08*</td>
</tr>
<tr>
<td><strong>Model 2 (Predicting SC$_{severity}$)</strong></td>
<td>.05</td>
<td>6.95**</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consumer's Age</td>
<td></td>
<td></td>
<td>.19</td>
<td>.06</td>
<td>.21</td>
<td>3.42**</td>
</tr>
<tr>
<td>Total Life Changes</td>
<td></td>
<td></td>
<td>.31</td>
<td>.17</td>
<td>.11</td>
<td>1.84</td>
</tr>
</tbody>
</table>

*Note:* $p < .05$; **$p < .01$; ***$p < .001$; SC$_{frequency}$ = Frequency of Secondary Conditions; SC$_{severity}$ = Sum of Severity Ratings Associated with Secondary Conditions.

conditions. These findings were supported to a large extent by models derived from an independent sample (See Appendix F).

For Model 2 ($R^2 = .05$, $F(2, 254) = 6.95$, $p < .05$), age was a significant predictor of SC$_{severity}$ ($b_1 = .19$, $\beta_1 = .21$, $t(255) = 3.42$, $p < .05$). In Model 2, age uniquely accounted 4.4% of the variance in the criterion variable, the SC$_{severity}$. Model 2 predicts that an increase of one year in age is related to an increase of .19 units in the SC$_{severity}$ (CI = .08 to .29 units in SC$_{severity}$). In Model 2, there was a trend toward significance for the predictor, life changes ($b_2 = .31$; $\beta_2 = .31$, $t(255) = 1.84$, $p = .07$), which uniquely...
accounted for 1.3% of the variance in the $SC_{\text{severity}}$. For information regarding the validation of this model, see Appendix F.

**Exploratory Analyses**

For the first series of CART analyses, age, gender, overall severity level of disability, type of living arrangement, number of IP objectives addressing specific secondary conditions, and county of residence’s urban-rural classification were used as predictors. In addition, continuous variables were standardized to facilitate interpretation of cut-off points. Optimal trees for the present study were chosen using criteria based on the smallest cross-validation relative error rate\(^2\) regardless of tree size and are discussed in terms of positive and negative cumulative effects and positive and negative compensatory effects.

Several series of CART analyses were conducted to test the general exploratory hypotheses of the present study. First, a preliminary series of CART analyses are discussed. These analyses included all hypothesized predictors and were conducted for the $SC_{\text{severity}}$ and for the $SC_{\text{frequency}}$. Results from CART analyses of a second, independent sample are also examined. Next, a series of CART analyses, which excluded one of the hypothesized predictors (i.e., number of IP objectives addressing secondary conditions), is described and is discussed in terms of the exploratory hypotheses of the present study.

\(^2\) The cross-validation relative error rate (or test sample error rate) is derived from the external test sample and is one measure of relative cost providing information about potential trees. The cross-validation relative error fluctuates with the predictive accuracy of different sized trees. Because Breiman et al. (1984) have shown that cross-validation has a strong tendency to overstate the error rate for small regression trees (i.e., trees with fewer than 10 to 15 terminal nodes), they encourage the additional use of an independent sample to identify the optimal tree.
Finally, results of CART analyses conducted with an independent sample using the same reduced predictor pool are described, discussed, and compared to the findings from the study sample.

**Preliminary CART analyses.** The CART analyses of the two secondary condition summary scores resulted in similar and fairly uncomplicated optimal trees that had two terminal nodes. For the trees modeling SC\textsubscript{frequency} and SC\textsubscript{severity}, the cross-validated relative error rates were 0.88 +/- .06 and .81 +/- .08, and the resubstitution relative errors\textsuperscript{3} were .80 and .74, respectively. The latter indices correspond to .20 and .26 as estimates of the R-squared values for these trees. The root nodes of both trees were split on the predictor variable, number of IP objectives addressing secondary conditions (TOT IP; see Figure 3). Participants with a total number of IP objectives addressing secondary conditions that was less than or equal to 1.5 standard deviations above the mean went left to terminal node 2, and participants with a total number of IP objectives that was more than 1.5 standard deviations above the mean went right to terminal node 3. For the trees modeling SC\textsubscript{frequency} and SC\textsubscript{severity}, terminal node 2 comprised participants whose average experience of secondary conditions (M = -.14, SD = .90 and M = -.16, SD = .82, respectively) was approximately one-sixth standard deviation below the mean, and terminal node 3

\textsuperscript{3} The resubstitution relative error is an internal measure describing the learning sample (i.e., the entire sample) and is the other measure of relative cost used when considering potential trees. The resubstitution relative error decreases as the number of terminal nodes on a tree increases. It indicates the misclassification rate for the data from which the tree was grown, but does not give valid estimates of a tree’s predictive accuracy. Instead, it is used to compare same-sized trees based on different variables and provides critical information to the process of pruning. The R\textsuperscript{2} was estimated by subtracting the relative resubstitution cost from one (see Breiman et al., 1984).
comprised participants whose average experience of secondary conditions ($M = 1.50$, $SD = .99$ and $M = 1.66$, $SD = 1.18$, respectively) was approximately one and a half standard deviations above the mean.

These trees illustrate that a potentiating level of number of IP objectives addressing secondary conditions is associated with a greater experience of secondary conditions. As such, the presence of these levels may be viewed as a risk factor and the absence as a protective factor. The brevity of the trees did not allow for full exploration the posited exploratory hypotheses. Importantly, pathways of compensation could not be explored, and it was posited that these types of effects may demonstrate how protective levels in number of IP objectives might diminish the effects of other risk factors (i.e., total life changes). A potential reason for the brevity of each tree concerns the high correlations that existed between number of IP objectives addressing secondary conditions and indices of the experience of secondary conditions. Pearson product moment correlations describing the relationships between the number of IP objectives addressing secondary conditions and the criterion variables, SCfrequency and SCseverity, were significant at the .05 level ($r = .43$ and $r = .52$, respectively). Interestingly, CART determined that total life changes was the only surrogate\(^4\) for both trees, and since each tree resulted in only one

\(^4\) CART provides information about the best surrogates for each split. These are the predictors that would best approximate the assignment of specific participants into the child nodes resulting from the primary split criterion. Surrogates are ranked by their ability to match the primary split on a case-by-case basis. The indices of this ability are summed for each variable over each node and are totaled. The totals are scaled relative to the best performing variable resulting in a ranking of variables on the importance measure. This measure is offered by CART to examine the potential masking of predictors by superiorly important variables. Potentially, no predictor variable will be able to mimic the groupings.
split, this predictor was the variable second in importance to number of IP objectives. This
description is important to the stress-related hypotheses of the present study and is
relevant to the issue of potential suppression or masking of total life changes in these
preliminary analyses.

Figure 3. Optimal regression tree modeling the frequency of secondary conditions (SC_{Freq})
and the sum of severity ratings associated with secondary conditions (SC_{Sev}). All
predictors were considered. (Total IP = number of IP objectives addressing secondary
conditions).

of participants achieved by the primary splitting rule. In this case, CART does not offer a
surrogate (see Breiman et al., 1984).
Validation with an independent sample (all hypothesized predictors). Validation of these preliminary CART analyses was conducted using an independent sample. (This sample also provided the data used in the validation phases of the regression analyses. A detailed description of this independent sample is available in Appendix F). For the trees modeling \( SC_{\text{frequency}} \) and \( SC_{\text{severity}} \), the cross-validated relative error rates were 0.67 +/- .04 and 0.69 +/- .05, and the resubstitution relative errors were .55 and .62, respectively. The latter indices correspond to .45 and .38 as estimates of the R-squared values for these trees. These analyses resulted in optimal trees with seven and five terminal nodes, respectively. As in the preliminary CART analyses (above), number of individual plans addressing secondary conditions provided the primary split on the root nodes for both trees. The increased complexities of these trees derived from this larger independent sample provides some evidence that the predictiveness of less highly related independent variables may have been masked in the first series of CART analyses conducted with the smaller, main study sample. The larger R-squared values for these more complex trees accounted for 25% and 12% more of the variance in \( SC_{\text{frequency}} \) and \( SC_{\text{severity}} \), respectively. While it is not surprising that the estimates of R-squared increased with an increased number of predictors, one must also the consider that the inclusion of important predictors improved the description of the relationships among relevant variables.

**CART analyses of study sample (reduced set of predictors).** To further test the general exploratory hypotheses of the present study, a second series of CART analyses was conducted with the exclusion of the predictor variable, number of IP objectives addressing secondary conditions. In the analysis of \( SC_{\text{frequency}} \), CART determined that there...
were no trees with lower cross-validation relative error rates than the rate associated with the smallest tree (i.e., a tree consisting of only the root node). Therefore, CART did not grow a tree for the SC_{frequency}.  

Although no tree was grown for SC_{frequency} using a reduced set of predictors, the tree modeling SC_{severity} is described for this series of CART analyses. Importantly, the increased complexity of this tree compared to the tree depicted in Figure 3 facilitated examination of the hypotheses regarding cumulative and compensatory effects posited in the present study. The optimal tree modeling SC_{severity} had six terminal nodes. The cross-validated relative error rate was 0.96 +/- .04, and the resubstitution relative error rate was 0.79. The latter error rate corresponds to an R-squared estimate of .21 for this tree. The root node was split on the predictor variable, overall severity level of disability (see Figure 4). Note that the split on age in node 9 was necessary to reduce within-group variability, yet the small size of node 10 (N = 2) resulting from the split probably comprises idiosyncratic individuals. Discussion of this optimal tree will therefore not include details concerning this node.

---

5 Least-squares (LS) regression is the default node-splitting method used by CART. The alternative method is Least Absolute Deviation (LAD). CART offers an alternative because LS has been shown to be sensitive to outliers. LAD uses the mean squared error, and thus is less affected by the presence of outliers (Breiman et al., 1984). This alternative node-splitting method for regression trees was applied to the modeling of SC_{frequency}, yielding similar results. As a last resort and only for comparison to a model derived from an independent sample, CART's select command (i.e., trees are grown without the cross-validation testing) was used to grow an exploratory tree. This tree suggested transactional relationships of predictor variables, but the patterns are not similar to the analogous tree modeling SC_{frequency} for the validation sample (see below). This is not surprising since the predictive performance of this exploratory tree is probably poor given its cross-validated relative error rate (i.e., 1.11 +/- .08).
In terms of the hypotheses posited, this tree demonstrated a negative cumulative effect (see pathway in Figure 4 connected by nodes 1, 3, 5, and 7). Specifically, the combined deleterious effects of the personal attributes, overall disability severity and age, were compounded by the deleterious effect of the environmental attribute, total life changes. A fuller description of this pathway is as follows. Node 3 consists of 183 participants with higher overall disability severity (i.e., more severe than two-thirds of a standard deviation below the mean) whose average SC\textsubscript{severity} is one-sixth standard deviations above the mean. Node 5 consists of 80 older participants (i.e., more than one tenth of a standard deviation above the mean age) who were older and had greater overall disability severity. This subgroup is almost one-half of a standard deviation above the mean on SC\textsubscript{severity}. Node 7 consists of 37 participants who experienced an average number of life changes that was greater than one-quarter standard deviation below the mean of total life changes. This node contains a subset of participants who had greater overall disability severity, were older, and had more total life changes than other participants. The subgroup in terminal node 7 had an average SC\textsubscript{severity} that was about three quarters of a standard deviation above the mean, indicating higher estimates of limitation associated with secondary conditions. Other effects illustrated in this tree can be interpreted similarly.

This tree also illustrated two pathways that provided support for the hypothesis of positive compensation. In the first pathway connected by nodes 1, 3, and 4, the negative effect of having a potentiating level of overall disability severity was transcended by the positive compensatory effect of younger age. This effect resulted in an average SC\textsubscript{severity} that approximated the mean. In the second pathway connected by nodes 1, 3, 5, and 6,
Figure 4. Optimal regression tree modeling the sum of severity ratings associated with secondary conditions. The predictor, number of IP objectives, was excluded from the analysis. (TOT LC = number of life changes, Overall SEV = overall disability severity).
positive compensation was affected by the experience of fewer total life changes. This effect protected 43 individuals, to some extent, from the negative impacts of greater overall disability severity and older age, reducing their average $SC_{severity}$ from about one half of a standard deviation above the mean to about one-fifth a standard deviation above the mean. In the first pathway, the positive compensatory effect of a personal attribute diminished the deleterious effect of another personal attribute, and in the second pathway, an environmental attribute ameliorated the combined negative effects of two personal attributes. Finally, there was no evidence of positive cumulative effects or negative compensatory effects in this regression tree.

**Validation with an independent sample (reduced set of predictors).** For the purposes of testing the replicability of these patterns of prediction supporting exploratory hypotheses, CART analyses with the same criterion variable and predictor pool were conducted on an independent sample (for a description of this sample, see Appendix F). The resulting validation tree modeling $SC_{severity}$ had one fewer terminal nodes than the study tree; however, if one considers node 9 of the study tree to be a terminal node, this discrepancy is resolved. For the validation tree (see Figure 5), the cross-validated relative error rate was 0.91 +/- .03, and the resubstitution relative error rate was .78. The latter index corresponds to .22 as an estimate of the R-squared value for this tree, a very similar coefficient of determination to that of the study tree also modeling $SC_{severity}$ with a reduced set of predictors.

The validation tree modeling $SC_{severity}$ demonstrated a positive cumulative effect (i.e., see pathway connected by nodes 1, 2, 4, and 8). Specifically, the beneficial effect of
the personal attribute, lower overall disability severity, was improved by the beneficial effect of another personal attribute, younger age, and by the beneficial effect of the environmental attribute, fewer life changes. The 284 participants within the intersection of the lower overall disability severity, age, and total life changes distributions experienced an average $SC_{severity}$ that was about one-half of a standard deviation below the mean, indicating lower estimates of limitation associated with secondary conditions. This tree also illustrated two pathways that provided support for the hypothesis of negative compensation. In the first pathway connected by nodes 1, 2, and 5, the beneficial effect of lower overall disability severity was diminished by the negative compensatory effect of older age, resulting in an average $SC_{severity}$ that was about a third standard deviation higher than the mean. In the second pathway connected by nodes 1, 2, 4, and 9, the combined beneficial effects of two personal attributes, lower overall disability severity and younger age, were predominated by the negative compensatory effect of a potentiating total of life changes, which resulted in an average $SC_{severity}$ that was about a quarter standard deviation above the mean. These individuals ($N = 92$) may have experienced the salubrious effects of having a protective level of overall disability severity and of being a member of a younger subgroup of the validation sample; however, these effects were abated by the negative compensatory effect of experiencing a potentiating number of life changes. To summarize, in the first pathway of negative compensation, the beneficial effects of a personal attribute (i.e., lower overall disability severity) were diminished by the negative effects of another personal attribute (i.e., older age), and in the second pathway, the combined positive effects of two personal attributes (i.e., lower overall disability severity
and younger age) were negatively compensated for by the effects of an environmental attribute (i.e., higher number of life changes). For this validation tree, there was also support for the negative accumulation and positive compensation hypotheses. A negative cumulative effect was demonstrated in the pathway connected by nodes 1, 3, and 7. For the eleven individuals represented in node 7, the combined deleterious effects of greater overall disability severity and of living in an independent residence or a supported living situation resulted in an average $SC_{\text{severity}}$ that was about one and three quarters standard deviations above the mean. Positive compensation was demonstrated in the pathway connected by nodes 1, 3, and 6. Here persons experiencing the negative effects of greater overall disability severity were protected, to some extent, by residing in a family or foster home, an intensive care or non-intensive group home, an ICF-MR, or a nursing home. This positive compensatory effect resulted in an average $SC_{\text{severity}}$ that was less than one-half standard deviations above the mean.

Upon comparison of the trees modeling $SC_{\text{severity}}$ for the study sample and for the validation sample, it was noted that, if one disregards the specific indices and split criterions, the two trees demonstrate patterns of accumulation and compensation that appear to be mirror images of one another. Specifically, the negative cumulative effect of the main study tree (i.e., pathway connected by nodes 1, 3, 5, and 7) was depicted as a positive cumulative effect for the validation tree (i.e., pathway connected by 1, 2, 4, and 8). Additionally, the positive compensatory effects of the main study tree (e.g., pathway connected by nodes 1, 3, and 4) were similar in patterns of prediction to the negative compensatory effects of the validation tree (e.g., pathway connected by nodes 1, 2, and 5). These findings are examined further in the discussion section.
The exploratory hypotheses regarding prediction of SC frequency were also tested with the second, independent sample. The resulting optimal tree had ten terminal nodes (see Figure 6). For this tree, the cross-validated relative error rate was .78 +/- .04, and the resubstitution relative error rate was .64. The latter index corresponds to .36 as an estimate of the R-squared value for this tree. Since no tree was grown for SC frequency from the study sample, no comparison can be made to this coefficient of determination.

The tree modeling SC frequency for the second, independent sample demonstrated support for each exploratory hypothesis (i.e., positive and negative cumulative effects as well as positive and negative compensation). A positive cumulative effect is demonstrated in the pathway connecting nodes 1, 2, 4, 8, and 14. Here, the 155 participants with the combined positive effects of fewer total life changes; residing in an independent residence, a family or foster home, a supported living situation, or a non-intensive group home; younger age; and lower overall disability severity resulted in an average SC frequency that was about two-thirds of a standard deviation below the mean, indicating a lower frequency of secondary conditions associated with activity limitation. A negative cumulative effect, in turn, resulted from the combination of a potentiating total of life changes, a potentiating level of overall disability severity, and a residence that was not a medically intensive situation (i.e., independent residence, a family or foster home, a supported living situation, or a non-intensive group home; see pathway connected by nodes 1, 3, 7, and 13).

Terminal node 13 contains a subset of participants who experienced this effect and had an average SC frequency that was about one and one-half standard deviations above the mean.
Figure 5. Optimal regression tree modeling the validation sample data for the sum of severity ratings associated with secondary conditions. Number of individual plans was excluded from the analysis. (TOT LC = number of life changes, Overall SEV = overall disability severity).
This tree demonstrated support for the exploratory hypothesis regarding negative compensatory effects in four different pathways. In particular, the pathway connected by nodes 1, 2, and 5 revealed that the beneficial effect of experiencing fewer life changes was negatively counterbalanced by the deleterious effect of being a resident of an intensive care group home, an ICF-MR, or a nursing home. This negative compensatory effect resulted in an average SC_frequency that was more than a third of a standard deviation above the mean. In addition, the pathway connecting nodes 1, 2, 4, and 9 suggested that the combined beneficial effects of experiencing fewer life changes and of residing in an independent residence, a family or foster home, a supported living situation, or a non-intensive group home were predominated by the negative effect of being older. The net result of the interactions of these predictors was a subgroup of participants with an average SC_frequency that was about one and one-third standard deviations above the mean. A third example of negative compensation involves the pathway connected by nodes 1, 2, 4, 8, and 15. Here the combined beneficial effects of fewer life changes, of residing somewhere besides in a medically intensive living arrangement (i.e., independent residence, a family or foster home, a supported living situation, or a non-intensive group home), and of being younger were diminished by the negative effect of greater overall disability severity. This effect resulted in an average SC_frequency that was approximately a quarter standard deviations below the mean. A fourth example of negative compensation involved the pathway connected by nodes 1, 3, 6, 11, 17, and 19. At first, this pathway demonstrates the amelioration of the negative effect of a greater total of life changes by the beneficial effect of lower overall disability severity. However, the final negative compensatory effects of
Figure 6. Optimal regression tree modeling the independent sample data for frequency of secondary conditions. Number of individual plans was excluded from the analysis. (TOT LC = number of life changes, Overall SEV = overall disability severity; RES 1 = independent residence, RES 2 = family or foster home, RES 3 = supported living, RES 4, non-intensive group home, RES 5 = intensive care group home, intermediate care facility (ICF-MR), or a nursing home).
older age, of experiencing an even greater total of life changes, and of being female
defined a subgroup of participants with an average SC\text{frequency} that was approximately one
and one-sixth standard deviations above the mean.

Finally, this tree demonstrated support for the exploratory hypothesis regarding
positive compensation. The clearest evidence was illustrated in the pathways connected by
nodes 1, 3, 6, and 10 and by nodes 1, 3, 7, and 12. In the first pathway, the negative
impact of experiencing a potentiating total of life changes was overridden by the positive
compensatory effects of lower overall disability severity and younger age. The 73 persons
comprised in node 10 had an average SC\text{frequency} that was one-tenth of a standard deviation
below the mean. In the second pathway, the combined deleterious effects of experiencing
a potentiating total of life changes and of having greater overall disability severity were
lessened by the positive compensatory effect of living in a non-intensive group home. The
resulting node had an average SC\text{frequency} that was about one-sixth of a standard deviation
above the mean. Finally, two additional pathways demonstrated support for the positive
compensation hypothesis, specifically those connected by nodes 1, 3, 6, 11, and 16 and by
nodes 1, 3, 6, 11, 17, and 18. Although these positive compensatory effects are less
straightforward, they do provide additional examples of the complex ways personal and
environmental resources might combine to yield a positive compensatory effect.

Discussion

Secondary conditions are major sources of limitation in the lives of persons with
disabilities (Brandt & Pope, 1997). Research informing how these secondary conditions
might be prevented at primary, secondary and tertiary levels is needed to increase the cost-
effectiveness and success of systems of support that enable populations with
developmental disabilities (Pope, 1992). Although an understanding of how stress
influences health has improved prevention, treatment, and activity programs in the general
population, there is a lack of research conducted with persons with developmental
disabilities. That is, there is little information on the measurement of stress, the
relationship between stress and health, the relationship between stress and the experience
of secondary conditions, and the potential buffers (e.g., personal and psychosocial
attributes) that ameliorate the negative effects of stress on the experience of secondary
conditions among adults with developmental disabilities. This research project is a
preliminary effort in a research agenda aimed at addressing these issues.

The present study investigated the predictive utility of life changes for
understanding the experience of secondary conditions in a sample of adults with
developmental disabilities. Analyses revealed that the relationship between life changes
and the frequency of secondary conditions was significant, whereas the relationship
between life changes and the sum of severity ratings associated with secondary conditions
exhibited a trend toward significance. Both of these relationships were significant in the
validation models derived from an independent sample of adult consumers of Montana
DDP. From a Bayesian perspective (for reviews, see Green, 1993; McClure & Suen,
1994), each of these findings supports a priori assumptions regarding the positive
directionality of the relationship between life change and the experience of secondary
conditions. As such, each has practical significance for future studies of health-related
effects of stress.
Consistent with previous studies of the relationship between life events and health conducted in other populations, the relationships demonstrated in the present study were weak to modest, explaining a small proportion of the variance in the health-related outcome measures. Traditional explanations for the modest strength of such relationships include methodological concerns of measuring life events and health (Cohen, 1988; Herbert & Cohen, 1996; Hubbard, 1991; Thoits, 1983), the role of perception of stress as an important mediator of the relationship between life events and health (Lazarus & Folkman, 1984), and the contributions of personal and environmental resources to the relationship between stress and health (Clements & Turpin, 2000; Costa & McCrae, 1993; Thoits, 1983; Wallace, 1999). The latter two explanations speak to stress researchers' consistent observations of individual differences in the relationships between health-related outcomes and life events (for a review, see Cohen & Herbert, 1996). That is, some people who experience a given number of life events demonstrate poor health while others do not. This description, in conjunction with recruitment efforts to include equal numbers of healthy and unhealthy persons in the study sample, provided a possible explanation for the weak relationships between life change and the experience of secondary conditions. Potentially, the successful adaptation of healthy participants to life changes may have diminished the strength of the relationship between stress and the experience of secondary conditions in the study sample. The validation sample was recruited with a blanket survey of all adult consumers of Montana DDP and thus may represent a broader range of the health in this population. In this sample, life changes accounted for a larger proportion of the variance in the frequency of secondary conditions.
and was a significant predictor of the sum of severity ratings associated with secondary conditions. From a statistical standpoint, this improvement in explanatory power is explained, to some extent, by the increase in sample size. However, comparisons of the effect sizes associated with age across variates modeling the frequency of secondary conditions and the sum of severity ratings associated with secondary conditions for the main study sample and the validation sample revealed little variation (i.e., $f_{freq}^2 = .07$ and $f_{sev}^2 = .05$ compared to $f_{freq}^2 = .08$ and $f_{sev}^2 = .06$, respectively), whereas similar comparisons of the effect sizes associated with total life changes revealed that its predictive strength was substantially lower in the main study regression analyses than it was in the validation regression analyses (i.e., $f_{freq}^2 = .02$ and $f_{sev}^2 = .01$ compared to $f_{freq}^2 = .17$ and $f_{sev}^2 = .14$, respectively). This may further indicate important differences between the two independent samples in the proportions of successful and unsuccessful adapters. (For further discussion of the different model specifications of the study and validation samples, see Appendix F).

Findings from the present study resonate with those from a related field of research, subjective well-being. In their review of the past thirty years of research on subjective well being, Diener, Suh, Lucas, and Smith (1999) distinguished between top-down and bottom-up processes that influence subjective well-being. Early subjective well-being studies guided by the bottom-up approach focused on external, objective variables that if present, would presumably allow an individual to pursue universal human goals and hence, be happy. Research using the bottom-up approach explained a disappointingly small proportion of the variance in subjective well-being. This predicated the shift in
subjective well-being research to the top-down approach, focusing on personal factors that determine how external events are perceived and experienced. Current directions within the field are derived from models of person-environment interactions. These models assert that personal and environmental characteristics interact dynamically and reciprocally to affect subjective well-being. Current goals within the subjective well-being field are to elevate the sophistication of research methodologies so that these complex hypotheses can be tested. The analogies of Diener et al.'s (1999) historical review to the past thirty years of investigations of the relationship between stress and health are straightforward. Lazarus and Folkman (1984) summarized perspectives that have been guiding stress researchers for over 15 years:

"...a given problem of adaptation must be viewed transactionally; it must be seen as a product of the interplay between the person and his or her environment. For example, rather than being solely a person problem, vulnerability arises from being in certain environmental contexts that interact with relevant person factors. Interventions must also be process-oriented; what has happened and is happening for the person must be studied across diverse incidents and/or contexts" (p. 374).

Transactional processes between person and environment are also integral to evolving conceptualizations of the disablement process associated with secondary conditions (Brandt & Pope, 1997; Verbrugge & Jette, 1994; WHO, 1999). Primary findings of the present study describe the relationship between life changes and the experience of secondary conditions in bivariate and unidirectional terms as opposed to transactionally. However, the relationship was described in a context of adults with developmental
disabilities, which had not been done heretofore. Furthermore, the evidence of weak to modest relationships between life changes and secondary conditions in this population sets a similar course of investigations with this population to the one guiding studies with other populations. The exploratory goal of the present study served as a first step on this course of inquiry into the complexities of the relationship between life changes and secondary conditions among adults with developmental disabilities.

The exploratory analyses of this research project provided initiatory insight into the roles that personal and environmental resources have in moderating the relationship between stress and the experience of secondary conditions. It is essential to keep in mind, however, that the exploratory analyses were limited in scope to the description of when this relationship varied in strength and not why (Thoits, 1983). Findings of the exploratory analyses of the present study can be summarized, to some extent, by Thoits’ (1983) observation regarding the moderation of the relationship between life events and aspects of health. "In Lazarfeldian terms (Kendall and Lazarsfeld, 1950), the presence or absence of vulnerability factors specifies the relationship between events and disturbance; the relationship was weaker when resistance factors are relatively present and stronger when such factors are absent" (p. 80). Furthermore, the added dimension of CART methodology (i.e., CART) facilitated exploratory investigations of the transactional relationships of risk and protective factors in the present study.

In the current research, the moderating effects of personal and environmental attributes were hypothesized to occur in patterns of accumulation and compensation. The presence of protective factors were posited to be important in patterns of positive...
accumulation and positive compensation, and the absence of such factors were posited to be important in patterns of negative accumulation and negative compensation. In the preliminary exploratory analyses of the present study, the personal attributes (i.e., age, gender, and overall disability severity level) and the environmental attributes (i.e., total life changes, number of IP objectives addressing secondary conditions, and county of residence’s urban-rural classification) were included as potential predictors of the experience of secondary conditions. Results of these analyses did not support hypothetical assertions regarding processes of accumulation and compensation. Moreover, the results did not provide support for the role of a number of IP objectives addressing secondary conditions as a protective environmental attribute. For example, because the optimal trees ended in only two terminal nodes, the question of whether IP objectives buffer the effect of a potentiating level of life events on the experience of secondary conditions could not be addressed.

The series of CART analyses performed without number of IP objectives addressing secondary conditions in the predictor pool provided the clearest support for the exploratory hypotheses of the present study regarding cumulative and compensatory effects. A notable exception was the lack of tree grown in the study sample for frequency of secondary conditions. However, other results of the CART analyses using the reduced set of predictors emphasized the utility of describing patterns of prediction beyond simple bivariate relationships. The tree modeling sum of severity ratings associated with secondary conditions for the study sample (see Figure 4) demonstrated support for negative accumulation and positive compensation, while the tree modeling the same
criterion variable for the validation sample (see Figure 5) demonstrated support for positive accumulation and negative compensation. Both trees demonstrated the transactional relationships that two personal attributes (i.e., overall disability severity and age) and one environmental attribute (i.e., total life changes) had in predicting the sum of severity ratings associated with secondary conditions. The validation tree modeling frequency of secondary conditions also provided support for the exploratory hypotheses. Examples of positive and negative cumulative effects as well as positive and negative compensatory effects demonstrated different pathways that led to varying frequencies of secondary conditions. This tree must be interpreted with some caution as it was not replicated to any extent with an independent sample.

Descriptive comparisons of the coefficient of determination from the regression of sum of severity ratings associated with secondary conditions and the respective CART analysis indicates the importance of examining these more complex pathways. In the prediction of the sum of severity ratings associated with secondary conditions, the regression analyses conducted with main study data and with validation data resulted in variates that accounted for a respective 5% and 16% of the variance, whereas CART’s main study and validation trees conducted with a reduced pool of predictors accounted for a respective 21% and 22% of the variance. From a clinical or practical standpoint (Ottenbacher, 1992), CART’s decision trees can inform effective distribution of health promotion resources to persons who may have more potential to benefit (e.g., see the two terminal nodes labeled 7, in Figures 4 and 5, respectively). That is, resources designed to influence the relationship between life change and the experience of secondary conditions

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.
can be directed to portions of the population where this relationship is most salient, thus maximizing the effect size of those interventions. Additionally, subgroups of individuals can be identified through different pathways of prediction, yet can share in a greater experience of secondary conditions. Individuals in need of health promotion can be identified with information about their personal or environmental resources. Distinctive profiles can suggest different health promotion strategies or interventions. For example, pathways to nodes 5 and 9 in Figure 5 resulted in similar means and standard deviations in the sum of severity ratings associated with secondary conditions, yet the pathway to node 5 might suggest health promotion strategies designed for persons experiencing age-related health changes such as losses in memory, sleep regularity, continence, and mobility (e.g., Buys & Rushworth, 1997; LeBlanc & Matson, 1997), whereas the pathway to node 9 might suggest more general stress-reduction strategies (e.g., Holmes, 1989; Lazarus & Folkman, 1984). Finally, because the predictor variable, total life changes, provided the primary split in the root node of the validation tree modeling frequency of secondary conditions, opportunities to interpret positive compensatory effects in terms of stress buffering were also provided. Importantly, this tree illustrated how the negative effects of total life changes can be buffered to lesser and greater degrees by various combinations of personal and environmental resources. For example, buffering of the negative effects of a greater total of life changes was provided by the positive compensatory effect of lower overall disability severity and younger age (see pathway connected by nodes 1, 3, 6, and 10). This effect resulted in an average \( SC_{\text{frequency}} \) that was one-tenth of a standard deviation below the mean. The buffering of the negative effects of a greater total of life changes and
greater overall disability severity was provided by the positive compensation of living in a non-intensive group home (see pathway connected by nodes 1, 3, 7, and 12). This effect resulted in an average $SC_{frequency}$ that was slightly more than one-tenth of a standard deviation above the mean.

In several ways, the theoretical framework of the present study facilitated interpretation of the cumulative and compensatory pathways connecting personal and environmental attributes and influencing the experience of secondary conditions for Montanans with developmental disabilities. In a broad manner, results of the exploratory analyses supported life-span developmental theory's conceptualizations of contextualism and transactional adaptation (Smith and Baltes, 1999). That is, the extent to which the environmental attribute, total life changes, contributes to an individual's resilience or vulnerability is affected by the personal attributes of the individual experiencing the changes. Also, results support life span developmental theory's concept of plasticity. Plasticity, an index of an individual's resources that can contribute positively or negatively to adaptation and developmental outcomes (Staudinger et al., 1995), was evident in the role the environmental attribute total life changes had in both positive and negative cumulative effects as well as in positive and negative compensatory effects. Specifically, the presence or absence of potentiating totals of life changes predicted lesser and greater experience of secondary conditions, respectively. This example is also consistent with the life-span theoretical conceptualization of risk and protective factors as being opposite ends of the same continuum and the conceptualization of the related concepts, resiliency and vulnerability, as being counterparts of one another (e.g., Rutter, 1987; Wallace et al.,
2000). Although the trees modeling sum of severity ratings associated with secondary conditions for the study sample and for the validation sample did not provide exact replicative findings, conceptualizing the attributes as risk or protective factors depending on their presence or absence allowed the respective pathways of negative accumulation (see Figure 4) and positive accumulation (see Figure 5) to be interpreted as complementary findings. From this perspective, the respective patterns of positive compensation (see Figure 4) and negative compensation (see Figure 5) could be similarly interpreted.

Finally, the importance of integrating each of these concepts of life-span developmental theory—contextualism, transactional adaptation, and plasticity—was highlighted by a further examination of the main study and validation trees modeling the sum of severity ratings associated with secondary conditions with a reduced set of predictors. Specifically, the environmental attribute, total life changes, provided a pertinent example illustrating the importance of contextual factors for identifying the levels of an attribute characterizing that attribute as a risk or protective factor. For the study sample tree modeling sum of severity ratings, a negative cumulative effect was illustrated through the combination of the three negative effects associated with greater overall disability severity, older age, and greater total of life changes. Here, the level of life change necessary to contribute to this combined effect (i.e., the level at which total life changes was an added risk factor) was greater than one quarter of a standard deviation below the total life changes' mean. In the validation tree, for persons benefitting from the
combined effects of lower overall disability severity and younger age, total life changes exceeding two-fifths of a standard deviation above the total life changes' mean behaved as a risk factor and was associated with an increase in the sum of severity ratings associated with secondary conditions. Comparatively, to contribute as a risk factor to the negative compensation effect present in the validation tree modeling sum of severity ratings associated with secondary conditions, life changes needed to exceed the level that defined it as a risk factor in the pattern of negative accumulation demonstrated in the main study tree. The trees demonstrated that variations in the personal resources with which total life changes had transactional relationships influenced the levels at which this environmental attribute behaved as a risk factor. A potential explanation is that these variations in age and overall disability severity were associated with different contextual factors and with variations in plasticity that in turn, led to variable moderation of the deleterious effects associated with life changes.

The Role of Stress in Health Promotion with Adults with Developmental Disabilities

In systems supporting adults with mental retardation, there are trends to move individuals into community integrated residences, places of employment, and recreational activities (e.g., Prouty & Lakin, 2000). Evaluations assessing the outcomes of such moves can be informed by the present study. Specifically, the interpretation of assessments measuring health before and after the move need to be considered carefully. If evaluations determine that an individual experiences decreases in health following a move toward community integration, one might interpret that the community integration has negative effects on health. This interpretation could argue against continued community integration.
In contrast, interpretations within the life-span developmental framework (e.g., Staudinger et al., 1995) and within the framework of secondary conditions (Marge, 1988; Pope, 1992), require added information on personal and environmental factors that would inform interventions for supporting community integration and promoting health. The findings of the exploratory analyses are only suggestive at this point and need further investigation, still they may shed some light on the current concern within the developmental disabilities community regarding the risks of community integration (e.g., Strauss, Kastner, & Shavelle, 1998).

During the early phases of de-institutionalization, the first persons to receive services in community settings had relatively resilient profiles, whereas today, as the process of de-institutionalization comes to a close, the persons moving into community settings from ICF-MRs and nursing homes have somewhat more risk factors contributing to their vulnerability (Prouty & Lakin, 2000). Findings from the exploratory analyses indicated that younger individuals with lower overall disability severity adapted successfully to a given number of life changes and experienced beneficial effects from this amount of change in terms of the experience of secondary conditions. This profile of individuals is consistent with early consumers of community based services. Alternatively, results of the present study suggest that older persons with greater overall disability severity experienced a similar amount of life change as detrimental to their health. To a large extent, these individuals could represent the newest consumers of community based services. Potentially, the supports in community based settings were developed as
appropriate resources for the more resilient members of this population and may be less appropriate for individuals with more vulnerable profiles. For example, methods effective in enabling choice and a sense of control have been shown to be important to successful adaptation (for a review, see Lachman, Ziff, & Spiro, 1994), and yet are not well defined for persons with more profound cognitive and communication impairments (Lohrmann-O’Rourke & Browder, 1998). Decreases in health may also be associated with specific life changes co-occurring with the programmatic move (e.g., new health care professionals, new transportation systems, a new diet, etc.) that may have a larger impact on a person with more medical needs.

Finally, the growth in the number of community based consumers may not be matched by similar growth in the number of community based resources. The American Association of Mental Retardation has proposed stability, well-being, and opportunities as the three defining characteristics of "wholesome environments". Stability ostensibly affords the individual predictability and control over her environment as well as facilitates the cultivation of adaptive personal and psychosocial resources. Inherent in the promotion of stability is the reduction of change and stress. Yet, "it is important to realize that the promotion of environmental stability often coexists in tension with one’s commitment to opportunities for growth and development" (AAMR, 1992). This tension has been well described in the aging literature as an equilibrium existing between needs for personal security and autonomy (Lawton, 1980, as cited in Field, 1992). One example heightening this tension is evident in the high rates of employment turnover among direct care staff (Razza, 1993; Sharrard, 1992). Recently, turnover among direct care staff has been
estimated to be as high as 300% in some areas of Montana (T. Spas, personal communication, October 20, 2000). This rate of change is a direct threat to the stability of environments and is an indirect threat to consumers' access to opportunities. Furthermore, if one conceptualizes total life changes as an index of stability and the sum of severity ratings associated with secondary conditions as an index of well-being, one might infer from the preliminary findings of the present study that turnover is also an indirect threat to the well-being of consumers.

First, descriptive statistics from the present study supported the observations of staff at the state DPHHSDDP. Specifically, the LCIADD item, "change in personal care attendant or direct care staff member", was the most frequently rated life change in the study and validation samples, contributing to the total life changes scores of approximately one half and two thirds of the individuals in each sample, respectively. Next, consider the levels at which total life changes behaved as a potentiating factor yielding greater sums of severity ratings associated with secondary conditions. These levels characterized total life changes as a risk factor contributing to a negative cumulative effect in the main study tree and a negative compensatory effect in the validation tree. To reiterate, these levels were one quarter standard deviation below and two fifths standard deviations above the total life changes mean, respectively. One might conceptualize these levels of total life change as thresholds on an index of stability. When these thresholds were exceeded, there was an associated decrease on an index of well-being for consumers (i.e., the sum of severity ratings associated with secondary conditions). It would seem reasonable for individual and system planners to minimize the probability of these turnovers within environments of all
consumers, but to prioritize these efforts for older individuals with greater overall disability severity.

Caveats, Limitations, and Future Research

Although, the present study provided important information on the relationship between stressful life changes and secondary conditions, results should be considered with the following limitations. First, there were several limitations associated with the measurement of life events and physical and psychosocial health. Problems with measuring life events included issues of reliability and validity, incomplete representation of important events and the number of confounded events on life event inventories, problems with assuming that each event is similar in predictive strength, and uncertainty about the causal direction between life events and poor physical and psychosocial health (Cohen, 1988; Thoits, 1983). There were additional problems with measuring physical and psychosocial health, and particularly using the present study’s method of report by surrogates (i.e. the direct care provider; see Appendix D). Although these respondents were selected because they were most familiar with each consumer and inter-rater reliability estimates were acceptable, there may have been systematic biases in their reporting (Andersen, Fitch, McLendon, & Meyers, 2000; Goode & Hogg, 1994; Todorov & Kirchner, 2000).

Importantly, measurement issues may have been of particular concern as the measures used in the present study were created or adjusted for this population (i.e., there were not established tools for measuring the constructs of secondary conditions and stress among adults with mental retardation or developmental disabilities). An avenue for future research entails the exploration of alternative tools and methodologies for measuring
secondary conditions and stress in this population.

Stress-related research conducted with other populations has identified various types of supports effective in moderating the influence of life change on the experience of secondary conditions. Some of these interventions minimize harmful effects of relocation and other life events by optimizing one's primary control. These interventions often include personal stress management strategies such as meditation and relaxation exercises, as well as creative problem solving and goal shifting (for a review, see Lachman et al., 1994). Though employed and studied among other populations, their use among persons with mental retardation should be broadened (AAMR, 1992) and their effects researched.

The concepts of multidirectionality and multidimensionality (Staudinger et al., 1995) elucidate further limitations of the present study. Multidirectionality implies that over the course of an individual's life, there will be gains, losses, and maintenance in terms of functioning within a domain of development and that across domains there can be concurrent gains, losses and maintenance. The multidimensional nature of human development implies that there are distinct categories within each domain of development in which the principles of multidirectionality apply. To use the obvious example of health, it is possible that life events may be associated with loss within this domain while simultaneously affecting other domains (e.g., self-help skills, self-esteem) beneficially. Additionally, within the domain of health, life changes may be associated with increased limitation due to certain secondary conditions (i.e. loss), but may be related to the secondary or tertiary management of other secondary conditions (i.e., gains or maintenance). Measurements within other domains were not included in the present

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.
study. Future research employing longitudinal assessments is needed to measure fluctuations within domains of competencies for individuals and to understand the directionality of the relationship between life changes and the experience of secondary conditions. In short, future investigations should allow for the testing of hypotheses generated from concepts of multidimensionality and multi-directionality. That is, a true appreciation of the multidirectional and multidimensional nature of development (Staudinger et al., 1995) would be reflected in longitudinal measures tapping a range of developmental domains that may be positively or negatively influenced by life changes as well (e.g., Ryff, 1989, 1995; WHO, 2000).

Finally, findings resulting from the use of a selected sample and a quasi-experimental design must be interpreted carefully due to the associated threats to internal and external validity (Cook & Campbell, 1979). For the present study, the differing Montana and federal eligibility requirements have implications for the external validity of any findings. The population of adults in Montana with developmental disabilities has some form of mental retardation or disability requiring supports and services similar to someone with mental retardation. Therefore, replications of findings from the present study regarding the relationships between life changes and secondary conditions are needed in states with varying eligibility criteria for adult developmental disabilities service programs.

The preliminary findings on age as an important predictor of the experience of secondary conditions also warrant further research. From a life-span developmental perspective, it will be important to investigate how age-related sources of development
contribute to this finding. In addition to studying the normative age-graded influences (i.e., biological and environmental aging changes), studying the nonnormative influences for this population (e.g., the various etiologies of mental retardation) and the normative history-graded influences (e.g., experiences with institutionalization) could provide critical insight into the mechanisms of adaptation. Kahana and Kahana’s (1998) temporal-spatial model of cumulative life stress is a potential model for describing these influences within a framework of stress and adaptation. Within this model, both early life crises (e.g., life threatening illness) and recent life events are considered essential for developing ‘life-course-relevant’ explanations of adaptation.

Results of the present study begin to describe the experience of life changes among adults with developmental disabilities. Future research may include a comparison study of the rates of life change experienced by demographically matched adults with and without developmental disabilities. If persons with developmental disabilities are experiencing significantly more stressful life changes than persons without developmental disabilities, this, in conjunction with increased vulnerability to stress, may partially explain the higher rates of health problems experienced by that population. Furthermore, future research is needed to understand the mechanisms by which personal and environmental characteristics moderate the relationship between life changes and health. While results from the exploratory analyses highlight the importance of studying the transactional relationships of personal and environmental attributes, future research is needed to identify what broader protective factors apply in this population. For example, in this population, how do protective personal resources such as personal control (Lachman et al., 1994), positive self
concept (Markus & Herzog, 1991), optimism (for a review, see Peterson, 2000), or hardiness (for a review, see Orr & Westman, 1990) combine with environmental protective factors such as social support (Kahn, 1994) to attenuate the positive relationship between stressful life change and health? Would models describing these relationships from the general population inform interventions that could effectively decrease the experience of secondary conditions among adults with mental retardation and associated developmental disabilities? If so, to what extent can the accessibility of those protective factors be increased in the communities and systems enabling this population?

Because the perception of stress is an important mediator in the relationship between life changes and health (Wallace, 1999), it will be important to examine how stress is perceived by persons with cognitive impairments and by persons living in supported settings. It will be important to determine if a consumer’s perception of stress, the caregiver’s perception of how stressed the consumer is, or if a combination of the two perceptions is most predictive of the health of consumers. Additionally, investigations of the psychological reactions to stress and their ability to moderate the influence of life change on health are needed. In this line of research, it will be important to discern the significance of the consumer’s psychological reaction to stressors and the care provider’s reaction to stressors in moderating the relationship between life changes and health. Future theoretical work, incorporating models of caregiving stress and caregiving well-being outcomes (e.g., Minnes, 1988; Minnes & Nachsen, 1998; for a review of other models, see Roccuforte, 1993) with models of individual stress and well-being outcomes (e.g.,
Wallace, 1999) would be beneficial to future research in this area. Potential resources that could inform such work include Berg, Meegan, and Deviney’s (1998) social-contextual model of coping with everyday problems, Gottlieb’s (1998) investigation of the impact of caregiver stress on a child consumers’ well-being, and Kahana, Kahana and Riley’s (1989) illumination of the relationships between institutional living, sense of control, and general learned helplessness.

Future research is also needed to understand the differences that exist in the physiological stress reaction among adults with developmental disabilities as compared to adults without developmental disabilities. Importantly, prolonged activation of the stress reaction, and specifically the prolonged presence of high levels of cortisol in the organism, causes deterioration of muscle, bone and nerve tissue and is related to the suppression of the immune system. Melzack (1998) surmises that many of the chronic pain syndromes and autoimmune diseases are pathologies resulting from these cellular insults. Tertiary prevention indications for successful management of such chronic conditions include the avoidance of psychological and physiological stressors (Lubkin, 1990), which supports Melzack’s contention. Additionally, the development of more effective coping strategies would be important to prevention programs. The neurological impairments associated with developmental disabilities could conceivably lead to prolonged activations of the stress reaction system (e.g., pathological hypothalamic functions in persons with Down Syndrome), which could contribute to the onset or exacerbation of secondary conditions such as joint and muscle pain, osteoporosis, and fatigue.

Whether a secondary conditions surveillance instrument or more traditional
measures of health would be more sensitive to the influence of life changes among persons with developmental disabilities remains an empirical question. Further research is needed to compare the secondary conditions surveillance instrument to traditional measures of health. These observations should be noted by system and individual planners. Finally, as discussed above, the reliability and validity of the estimations of limitation made by direct care providers needs to be further investigated. Future research is needed to compare the ratings of limitation made by proxy raters to the ratings made by consumers and to compare ratings made by proxy raters and consumers. Additionally ratings of limitation made by proxy and consumers must also be compared with ratings obtained from direct observation of consumers' behaviors. Research utilizing ecological momentary assessment (EMA; Shiffman & Stone, 1998) is being planned to longitudinally investigate further how stress of personal care assistants and of consumers are related to the well-being and continued employment of personal care assistants and to the experience of secondary conditions among adults with developmental disabilities. Additionally, this project will investigate further variability among consumer and proxy ratings of stress and health.

Conclusions

The present study highlighted the significance of secondary conditions and life changes in a population with developmental disabilities. However, a large proportion of the variance in secondary conditions was not explained by the bivariate relationship. The weak to modest relationships between life changes and the experience of secondary conditions underlined the significance of the exploratory analyses of the present study. These analyses examined the interactive and cumulative pathways of personal and
environmental factors in order to clarify some of the complexity involved in the relationships. Secondary conditions, by definition, are specific to persons with primary disabling conditions. However, the assumption of homogeneity in populations defined by concrete eligibility criteria is not useful when identifying opportunities and strategies for prevention. The multidimensional nature of human development requires that we move beyond traditional ways of thinking about these relationships to consider the more complex pathways through which life change may have an impact on health in populations with developmental disabilities. The present study was intended to move health promotion and disability research in that direction. This study is a first step in a broader research agenda that is geared towards increasing our understanding of the dynamic nature of primary disabilities and secondary conditions and the role that stress and life changes have in the transactional system of disablement.
References


National Center for Youth with Disabilities (1995). Transition from child to adult health care services: A national survey. The National Center for Youth With Disabilities, University of Minnesota, Minneapolis, MN.


Williams, B (1998, October). Keynote Address. Presented at the National Conference on Disability and Health: Building bridges for science and consumers, Dallas, TX.


Author Note

Meg Ann Traci, The Department of Psychology, The University of Montana.

This research is supported by a grant from the Office on Disability and Health, the Centers for Disease Control and Prevention, grant no. R04/CCR81412 with additional support from the Montana DDPAC and from the National Institute on Disability and Rehabilitation Research (NIDRR). Opinions are those of the author not those of the funding agencies. The current study was conducted in partial fulfillment of the requirements for the degree of doctor of philosophy at The University of Montana.

Special thanks are extended to all participants in the current research project— the consumers and their families, to personnel at the Montana Developmental Disabilities Program and private service corporations, and to the members of DDPAC and this project’s Advisory Panel. I feel exceedingly privileged to have had Dr. Wallace as my dissertation chair. Her counsel and labor were essential to the developmental perspective and analysis plans of this project. My current perspective on lifespan development has been infinitely enriched by her mentorship in this area; I am thankful to her for revealing to me its utility in understanding the effects of disability on individuals. I am indebted to Dr. Seekins, my boss and dissertation co-chair, for the inspiration, the positive reinforcement, and the meaningfulness, which he continuously injected into this project and throughout my graduate career. I would also like to thank my other dissertation committee members: Drs. Koester, Silverman, and Williams for their careful review and guidance on this project. I am also thankful for Dr. Forest’s informal participation in my dissertation committee. I greatly appreciate the encouragement and work of staff at the Research and Training Center on Rural Rehabilitation, especially Drs. Ravesloot and Szalda-Petree. To my friends and family, I am so glad to have had you as my cheerful traveling companions on this long road. Finally, I want to thank my husband for enriching the journey with his thoughtful comments, sense of humor and loving encouragement.
APPENDIX A: MONTANA HEALTH AND HUMAN SERVICES
DEVELOPMENTAL DISABILITIES PROGRAMS FOR ADULTS

The Department of Public Health and Human Services Developmental Disabilities Program mission statement reads: "The Developmental Disabilities Programs supports choices and opportunities for people with developmental disabilities in their communities" (DPHHSDDP, 2000). This mission reflects the national trend of de-institutionalization—the trend of moving individuals with mental retardation and associated developmental disabilities (MR/DD) into community-based settings. This trend was first evident in national descriptions of residential placements in fiscal year 1968 and continues to be reflected in the most current national descriptions (Prouty & Lakin, 2000). To accomplish their mission, Montana has organized a comprehensive system of services and supports to help people live in their communities and in cases involving chronic nursing care, the least restrictive environment possible. In many ways, the responses made by Society to the deficits associated with institutionalization nicely illustrate the role that deficits can play in positive compensation across the life-span. That is, the deplorable conditions observed within institutions (Carabello, 2000; Williams, 1998) and the related deficits observed in residents served and continue to serve as catalysts for positive change in programs of support facilitating consumers' adaptive capacities across their life spans (Bäckman & Dixon, 1992; Smith & Baltes, 1999).

The continuum of services within the DPHHSDDP includes: two state managed intermediate care facilities (ICF-MR) or institutions in Boulder and Glendive; systems of residential, supported living, work, and transportation programs operated by 44 local, not-for-profit corporations located in five service regions of the state; adaptive equipment
services provided by the Montana Adaptive Equipment Program located in the Montana University Affiliated Rural Institute on Disabilities (MUARID); and evaluation and diagnostic services provided in Missoula and Miles City by psychological services with the combined capacity to complete approximately 300 evaluations annually. Case management services are provided to assess, coordinate, and assure the delivery of services and supports required by Montanans with MR/DD who are 16 years or older. They are administered from nine offices of the DPHHSDDP and from four of the contracted not-for-profit corporations. Case management is the only entitlement program provided by the Montana DPHHSDDP. (See Table A.1 for approximate numbers of Montanans with MR/DD receiving the aforementioned services).

The Montana system includes high standards for services and treatment. These are operationalized on an annual basis for each consumer during an Individual Plan meeting. At each meeting, goals and objectives from the previous year are reviewed along with recently completed assessments (e.g., the Inventory for Client and Agency Planning (ICAP; Bruinicks et al., 1986)). Then goals and objectives for the upcoming year are set by the individual in conference with his case manager and with other relevant staff and/or designated support persons (e.g., family members or friends). The list of goals and objectives is the Individual Plan (IP) and serves as a support plan for the individual during the following year. Importantly, these plans can be changed or modified by the consumer at any time, making them flexible to her wants and needs. The Senior and Long Term Care Division of the Montana DPHHS provides Adult Protective Services (APS) to adults with developmental disabilities because of the increased risk of physical or mental injury,
neglect, sexual abuse or exploitation observed in this population. (For similar reasons, APS are also provided to adults with mental and physical disabilities and to persons over the age of 60). The goals of APS are to reduce the physical or mental harm experienced by a person as a result of abuse, neglect, or exploitation. Adult Protective Services are emergency intervention activities that may include: investigating complaints, coordinating family and community support resources, strengthening current living situations, developing and protecting personal financial resources and facilitating legal intervention.

The Administration on Developmental Disabilities (ADD) operates from the federal level to ensure high standards for programs of services, support and treatment. Relevant programs administered by the ADD are Developmental Disabilities Planning and Advisory Councils, Protection and Advocacy for Individuals with Developmental Disabilities, and University Affiliated Programs (UAPs). Each state is authorized by federal law (Developmental Disabilities Assistance and Bill of Rights Act, Part B) to have a Developmental Disabilities Planning and Advisory Council (DDPAC). The Montana DDPAC consists of 25 members, who were appointed by the governor. Each council is charged with the administration of federal funds in three areas: 1) assistance in the provision of services to persons with developmental disabilities; 2) assistance to state agencies involved in the planning process for persons with developmental disabilities; and 3) establishment of model programs that may involve, among other things, innovative techniques of habilitation and treatment or the training of service providers. The program of Protection and Advocacy for Individuals with Developmental Disabilities (PADD), is the designated protection and advocacy agency for Montanans with developmental
disabilities. PADDs are authorized by federal law (Developmental Disabilities Assistance and Bill of Rights Act, Part C) in each state to assist persons with developmental disabilities to exercise their full rights as citizens. In Montana, PADD is housed within the Montana Advocacy Program (MAP), which administers a total of five protection and advocacy programs for Montanans with disabilities. Like DDPAC, PADD is independent of other agencies that provide developmental disabilities services (e.g., Montana DPHHSDDP); unlike DDPAC, however, PADD is not a state agency. In FY 2000, the ADD appropriated $65,750,000 of its budget to supports for state DDPACs and $28,110,000 of its budget to state PADDs, and of these funds, ADD appropriated $408,984 and $267,768 to the Montana DDPAC and PADD. Finally, the ADD has created a national network of 61 university affiliated programs (UAPs) authorized by federal law (Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. Section 6000 et. Seq, Part D, sections 151-156) to assist individuals and state programs in the provision of interdisciplinary training, research, service demonstration programs, leverage of funds, and information dissemination. The activities of such programs are designed to increase and support the independence, productivity, and inclusion into the community of persons with developmental disabilities. For FY 2000, ADD appropriated $18,171,000 of its budget to support UAPs nationally. MUARID is part of this nationwide network and its activities are funded to support Montanans with developmental disabilities and to identify effective strategies of support for rural communities.

Eligibility for services is a function of definitions and assessments. Overall, the federal definition of developmental disabilities emphasizes the mental and/or physical

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.
aspects of the disability, the age of onset for the disability, the functional limitations caused by the disability, and the needs for supports to overcome such limitations as the essential criteria characterizing a developmental disability. The Montana state definition of developmental disabilities is more limited and identifies adults who are eligible for receiving services from the Montana DPHHSDDP as being persons who essentially require supports for mental retardation or similar handicapping conditions. The primary differences between the Montana state definition and the federal definition are: the ages of onset required for eligibility, which are prior to the age of 18 and prior the age of 22 for the state and federal age limits, respectively; the types of assessments required for eligibility determination, which include diagnostic assessments and functional needs assessments, respectively; and the needs determination criteria, mental retardation (or handicapping conditions requiring supports similar to those required for persons with mental retardation) and three or more areas of functional limitation requiring supports that increase participation in those areas, respectively. Montanans meeting this definition are placed on the waiting list for residential, supported living, work, and/or transportation services, but begin receiving case management services immediately.

For the date, June 30, 1999, Prouty and Lakin (2000) reported that there were 759 Montanans with MR/DD living in non-state residential facilities with 1-3 individuals, 196 Montanans living in non-state residential facilities with 4-6 individuals, 488 Montanans living in non-state residential facilities with 7-15 individuals, and 130 Montanans living in state residential facilities with 16 or more individuals. They estimated that 2,015 children and adults with MR/DD are living in the home of a family member. In total, these

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.
researchers described residential settings of an estimated 3,588 individuals receiving services from the Montana DPHHSDDP. Other individuals described in the Prouty and Lakin (2000) report are the 174 Montanans living in a nursing home. Their residential services are provided by the long-term care division of the Montana DPHHS, and they receive case management from the DPHHSDDP. Two-hundred and seventy four individuals are on the waiting list for residential services (Prouty & Lakin, 2000) and are receiving community supports and case management (Bullock & Ruzevich, 1999). With the addition of these individuals, the number of persons with MR/DD receiving services (solely through the DPHHSDDP or in combination with services provided by the long-term care division) increases to 4,026. This estimate is an increase from the number the state (1997) reported as the number of individuals receiving services (i.e., 3,540).

Estimates of the average cost of DDP services per Montanan with MR/DD is $14,822 for supported living, $10,262 for work services, and $465 for transportation services (T. Spas, personal communication, October 20, 2000). T. Spas, a regional director of case management for the Montana DPHHSDDP, reported that the estimate for residential services varies across types of settings. For example, the average annual cost for providing residential services to an individual in a group home was estimated to be $31,937, while the average cost of providing residential services to a person in the Boulder ICF-MR was estimated to be $150,000. This disparity is also reflected in the estimates provided by Prouty and Lakin (2000). They reported that the average annual cost of providing services to a Montanan with MR/DD in a community based setting (e.g., a group home) was $29,393 and this cost was $118,722 for a Montanan in an ICF-MR.
Table A1

Approximate Number of Montanans with Mental Retardation or a Developmental Disability Receiving Different Types of Services

<table>
<thead>
<tr>
<th>Type of Service</th>
<th>No. Consumers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case Management</td>
<td>2,230&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Work Services</td>
<td></td>
</tr>
<tr>
<td>Intensive adult work services</td>
<td>309&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Facility-based work services</td>
<td>689&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Supported employment services</td>
<td>217&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Combination supported work/facility-based work programs</td>
<td>280&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Senior Programs</td>
<td>113&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Residential Services</td>
<td></td>
</tr>
<tr>
<td>ICF-MR/Institution</td>
<td>138&lt;sup&gt;a,b&lt;/sup&gt;</td>
</tr>
<tr>
<td>Community Homes&lt;sup&gt;c&lt;/sup&gt;</td>
<td>293&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Intensive Care Community Homes&lt;sup&gt;d&lt;/sup&gt;</td>
<td>316&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Senior Community Homes&lt;sup&gt;e&lt;/sup&gt;</td>
<td>35&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Home of Family Member</td>
<td>2015&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>Foster Care Family Home/Host Family Home</td>
<td>204&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>Owned Residence</td>
<td>406&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>Supported Living&lt;sup&gt;f&lt;/sup&gt;</td>
<td>553&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Transportation Services</td>
<td>1421&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Waiting List (Community Supports)</td>
<td>274&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>Adaptive Equipment Services</td>
<td>250&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
</tbody>
</table>

Note: <sup>a</sup> Numbers obtained from DPHHSDDP; <sup>b</sup> numbers obtained from Prouty and Lakin (2000); <sup>c</sup> 3-8 residents; <sup>d</sup> approximately 6 residents with lower staff to consumer ratios than Community Homes; <sup>e</sup> 7-8 residents; <sup>f</sup> supported living can include any combination of residential, work, or transportation services.
facility. T. Spas (personal communication, October 20, 2000) also reported that these estimates of average cost would vary across the economic climates of the geographic locations specific to the private service corporations. For the majority of Montanans with MR/DD, these costs are shared between the state (approximately 28%-30% cost sharing) and Medicaid (approximately 70%-72% cost sharing). In 1999, individuals on the waiting list who were receiving only case management services began receiving community support services. Each of these individuals received $7,800 dollars in capitated funds to buy into self-determined services or programs. These services were funded by a special appropriation from the Montana legislature (Bullock & Ruzevich, 1999) and by a 70% match from Medicaid. Finally, there is a small number of Montanans with MR/DD whose services are entirely paid for by the general fund appropriated by the Montana legislature for DDP.

Health care utilization costs are essential components of any cost-benefit or cost-effectiveness study, but they are difficult to specify for individuals with MR/DD. The majority of medical bills for most Montanans with MR/DD are paid by Medicaid, yet estimates for the unique costs of medical care utilization are difficult to obtain from Medicaid records because of the number of other services paid for by Medicaid in this population (above). To complicate matters further, approximately 30% of Montanans with MR/DD are also receiving Medicare (D. Burke, personal communication, October 20, 2000). In these cases, medical bills are first addressed by Medicare then by Medicaid. Finally, for the small number of Montanans with MR/DD for whom the state general fund pays 100% of the cost of providing DDP services (i.e., these individuals are not eligible...
for Medicaid), medical costs are covered by pro-bono programs (e.g., dental programs), by private insurance, by personal income, or in rare cases, by DDP crisis funds. Methodologies that will take these various sources into account are being developed to estimate the costs of health care utilization for this population (S. Senninger and T. Lerner, personal communication, October 11, 2000). These cost estimates will be relevant to the present study as indices of the resources used to address the medical health of the population sampled.

The context of services created by the Montana DDP is similar to those created nationally. However, when generalizing the findings of the present study to other states' populations of adults with developmental disabilities or to future populations of adult Montanans with developmental disabilities, it will be important to note the differences among programs and delivery systems within which these groups are supported. For example, comparisons between data of the present study and data that might be collected in a state like Mississippi would be difficult given that over one half of Mississipians with MR/DD are served in facilities with 16 or more residents while the majority of Montanans with MR/DD, like residents of 39 other states, receive services in settings with six or fewer residents (Prouty & Lakin, 2000). Federal and state definitions are also important to the generalization of findings from the present study. The primary disability of individuals who participated in the present study was mental retardation or was a disability requiring services similar to those required by persons with mental retardation. For many adults who have impairments meeting the federal definition of developmental disability, cognitive functionality is not an area of limitation (McNeil, 1993). To summarize, it is important to
consider the contextual factors of the present study, an issue worth emphasizing since the system of support for persons with MR/DD is rapidly evolving.
APPENDIX B: POWER ANALYSIS FOR ORDINARY LEAST SQUARED REGRESSIONS

In order to estimate the power needed to replicate the effect size associated with the partial correlation coefficients of interest (i.e., $sr_2^2$) in the two regression analyses performed in this study (see below), post hoc power analyses were conducted. The process for these analyses (Cohen & Cohen, 1983) is outlined in the following five steps:

1. Set the acceptable risk of Type I error (i.e., $\alpha$) at .05.
2. Using the $R^2$ from the regression analyses run with all of the independent variables ($R_{\text{full}}^2$) and the $R^2$ from the regression analyses run with the omission of the independent variable, life changes ($R_{\text{omitted}}^2$), calculate the partial correlation coefficient for life changes by subtracting the latter from the former (i.e., $sr_2^2 = R_{\text{full}}^2 - R_{\text{omitted}}^2$).
3. Calculate the effect size ($f^2$) for the partial coefficient of the single independent variable, life change, using the equation: $f^2 = sr_2^2/(1-R_{\text{full}}^2)$.
4. Isolate the power value ($L$) using the equation: $n^*=(L/f^2) + k + 1$ so that the power value can be calculated using the equation: $L = f^2(n^*-k-1)$.
5. Enter the $L$ tables (Appendix tables E.1 and E.2 in Cohen & Cohen, 1983, pp. 526-527) at $k_B=1$. Scan the $L$ values in the corresponding row until the calculated $L$ value is most closely approximated in the table. Given the sample size and the $\alpha$ selected to produce the effect size for the partial correlation coefficients associated with life change in the regression analyses, the power identified for the column providing the closest approximation of the calculated $L$ value is reported as the power available in the present study (below).
In order to replicate the partial correlation coefficient associated with life change in the regression equation representing the frequency of secondary conditions as a function of age and life changes (i.e., \( \hat{r}^2 = 0.02 \)), one would need a research design providing power at the .60 level (\( k_B = 1, L = 4.90 \)). In order to replicate the partial correlation coefficient associated with life change in the regression equation representing the sum of severity ratings as a function of age and life changes (i.e., \( \hat{r}^2 = 0.01 \)), one would need a research design providing power at the .50 level (\( k_B = 1, L = 3.84 \)). Instead of extrapolating between entries in the table, the more conservative power estimates approximating the \( L \) values, 4.40 and 3.91, respectively, are reported here (Appendix table E.2 in Cohen & Cohen, 1983, p. 527).
Please provide your name, your relationship to the consumer, and the consumer’s name.

Consumer’s Name: ____________________________________________________________

Address:____________________________________________________________________

Phone Number: ______________________________________________________________

Facilitator’s Name: ___________________________________________________________

Relationship to the Consumer:

___ Direct Care Provider    ___ Case Manager    ___ Work Supervisor    ___ Guardian

Facilitator’s Employment Address:______________________________________________

Phone Number:________________________________________________________________
LIFE QUALITY & HEALTH IN MONTANA

PRIMARY DISABILITY AND PERSONAL INFORMATION

Consumer's Date of Birth: ____________________________

Male:____ Female:____ County of Residence:_________________________

Employment status
(Check ALL that apply):

___ Not currently employed
___ Retired
___ Home maker
___ Student
___ Employed Part-time (>20 Hrs/Wk)
___ Employed Full-time (>20 Hrs/Wk)
___ Sheltered Employment
___ Community Employment
___ Self-employment

Living Arrangements:

___ Independent residence
___ Family home
___ Supported living arrangement
___ Intensive care group home
___ Group home

Approximate date of disability/diagnosis:__________________________

___ Cerebral Palsy
___ Mental Retardation
___ Fetal Alcohol Syndrome
___ Down Syndrome
___ Autism
___ Epilepsy/Seizure Disorder
___ Spina Bifida
___ Hydrocephalus
___ Microcephalus
___ Muscular Dystrophy

Other developmental disability:____________________________________

Level of Mental Retardation or other disability:

Severe    Moderate    Mild
OVERALL HEALTH AND INDEPENDENCE INFORMATION

Overall, please describe the consumer’s HEALTH during the PAST TWELVE MONTHS:

Excellent  Good  Fair  Poor

Overall, please describe the INDEPENDENCE of the consumer- his or her ability to engage in desired activities such as work, recreation, or daily living over the past twelve months:

Excellent  Good  Fair  Poor

HEALTH CARE ACCESSIBILITY AND UTILIZATION INFORMATION

The following section relates to the amount and type of health care accessible to the consumer and to the amount of health care the consumer used during the past year.

1. How many days was the consumer hospitalized during the last year? And why?

# of Days: ____________________________________________________________

Reasons: ____________________________________________________________

____________________________________________________________________

How satisfied were you with the care and recommendations offered by the hospital?

0 1 2 3 4 5 6 7 8 9 10
Not Satisfied Somewhat Satisfied Very Satisfied
2. Did the consumer receive a general physical check-up this year?  ___ Yes  ___ No

   If “Yes,” was the physician conducting the physical familiar with the consumer’s medical history?  ___ Yes  ___ No

   How satisfied were you with the recommendations offered by the physician?

   \[\begin{array}{cccccccccc}
   0 & 1 & 2 & 3 & 4 & 5 & 6 & 7 & 8 & 9 & 10 \\
   \text{Not Satisfied} & \text{Somewhat Satisfied} & \text{Very Satisfied}
   \end{array}\]

3. During the past year, how many times did the consumer visit a health care professional for injuries, illnesses, or other complaints?

   \# of Visits: ____________________________________________________________

   Reasons: _________________________________________________________________

   _________________________________________________________________

   Overall, how satisfied were you with the recommendations offered during those visits?

   \[\begin{array}{cccccccccc}
   0 & 1 & 2 & 3 & 4 & 5 & 6 & 7 & 8 & 9 & 10 \\
   \text{Not Satisfied} & \text{Somewhat Satisfied} & \text{Very Satisfied}
   \end{array}\]

4. Did the consumer receive screening for breast or testicular cancer during the past year?  ___ Yes  ___ No  ___ Unknown

5. Did the consumer receive testing for sexually transmitted disease(s) during the past year?  ___ Yes  ___ No  ___ Unknown

   If “Yes,” why was testing conducted? _______________________________________

6. If the consumer is using sign language, a story board, a voice output system, or a computerized voice output system, is an interpreter or the technology available in health care settings so the consumer can communicate with the health care professionals?  ___ Yes  ___ No  ___ Not Applicable
A secondary condition is a problem experienced after a person has a primary disability. For example, a person with cerebral palsy may develop arthritis. Arthritis would then be a secondary condition for that person. Like a primary disability, a secondary condition may restrict a person's ability to do things independently.

On this questionnaire you will be asked to determine if a specific secondary condition has been a concern for the consumer during the past year. Next, you will estimate how much the condition limited the consumer during the past year. Finally, you will be asked to identify conditions that were on the consumer's Individual Plan (IP). Each item provides a brief description of a secondary disabling condition.

The questions following are divided into three general categories based on types of secondary conditions:

**Observed secondary conditions (pp. 9-14):** These conditions have symptoms or indicators which the consumer, you (the rater), friends, family, other staff, and/or health care professionals may have observed.

**Supplementary secondary conditions (pp. 14-15):** If the consumer experiences limitation due to problems associated with mobility, please complete the supplementary section of the questionnaire. If mobility is not a concern, proceed to the next section.

**Possible or identified medical secondary conditions (pp. 16-18):** These are conditions that have been formally diagnosed by an appropriate health care professional or conditions that you may be aware of or suspect are affecting the consumer's overall health and independence.

Before completing the rest of the questionnaire, please read through the following directions and examples carefully.
**IS THE SECONDARY CONDITION A CONCERN FOR THE CONSUMER?**

For each question, please determine if a condition is a concern for the consumer. You can judge whether a person has experienced or is experiencing a particular problem if you observe any of the following:

- **Consumer complaint**
  If the consumer has complained about a particular condition or has raised concerns about it, please rate the level of limitation the condition causes the consumer.

- **Rater concern**
  If you (the rater) have either observed the problem or condition, or are concerned about a condition, please rate the level of limitation the condition causes the consumer.

- **Family, friend, or staff concern**
  If family, friends, or other staff have mentioned a problem or condition regarding the consumer, please rate the level of limitation the condition causes the consumer.

- **Health Care Professional concern**
  If a health care professional (e.g., physician, nurse, psychologist, physical therapist, etc.) has raised it as a concern or diagnosed a particular condition, please rate the level of limitation the condition causes the consumer. Several items do require the attention and diagnosis of a physician.

- **Individual Plan objective [IP]**
  If a particular problem has been an ongoing issue that has been discussed at an Individual Plan meeting or is part of the written plan itself, please rate the level of limitation the condition causes the consumer. If there is an objective to address the concern, please check the IP box. If the condition is a concern, but an official IP objective has NOT been written, please leave this box blank.

Many conditions can be interrelated. Please, rate the levels of limitation caused by each of the conditions that the above sources have raised as a concern. Please do this without regard to one condition causing another. In other words, rate all conditions that apply.
HOW LIMITING IS THE SECONDARY CONDITION TO THE CONSUMER?

For each secondary condition, please estimate how much it limited the consumer DURING THE LAST YEAR. This rating should reflect the amount of limitation the consumer was experiencing during the time the condition was a concern (i.e. not an average over the span of a year). Please refer to this rating scale when indicating the level of limitation. If the condition has NOT been raised as a concern by any of the above sources, please rate the level of limitation caused by the condition a zero (0).

HOW DOES THE SECONDARY CONDITION LIMIT THE CONSUMER?
(Dimensions of participation: Enjoyable, Skillful, Efficient, Frequent, & Independent)

0 = No limitation
1 = Mild/infrequent limitation of activity (limits activity 1 to 5 hours per week)
2 = Moderate/occasional limitation of activity (limits activity 6 to 10 hours per week)
3 = Significant/chronic problem (limits activity 11 or more hours per week)

Dimensions of Limitation

When determining if some level of limitation is being experienced by the consumer, take a moment to consider the activities in which the consumer is involved:

- daily living activities (eating, sleeping, dressing, toileting, etc.)
- work activities (travel to and from work, job duties, etc.), and
- recreational activities (sports, game playing, reading, TV watching, social interaction, etc.).

When rating the severity of conditions experienced, consider how the consumer's engagement in his/her activities may be limited by a particular condition. For example, while experiencing the secondary condition:

- Was the activity enjoyable for the consumer?
- Were the consumer's skill level and efficiency maintained?
- Did the consumer engage in the activity as frequently as he/she did before the condition became a concern?
- Could the consumer be as independently involved in the activity as he/she was before the condition became a concern?

Examples of Limitation

How Secondary Conditions Might Directly Limit an Individual

The secondary condition, joint/muscle pain, can reduce the level of enjoyment or satisfaction in the activity. So an individual may continue to play basketball, but may enjoy the activity less because of the pain.
The condition, arthritis, can negatively affect the efficiency or performance of skills. This individual may complete work tasks at a certain rate that decreases when there are arthritic "flare-ups" or as the condition of arthritis worsens.

The condition, physical fitness or conditioning, can reduce the level of independence the consumer has in participating in an activity. This individual may need assistance when cleaning house or working in the yard because he or she is out of shape. This person would not need the assistance if physical fitness improved.

The condition, access (an item from the Supplementary Surveillance Instrument for individual's with mobility issues), can reduce an individual's levels of independence, enjoyment, and frequency for a variety of activities. This individual in a wheelchair may need more assistance to go out to eat at a restaurant that does not have any ramps, may not enjoy the experience as much, and may not go out to eat as often because of the condition of access.

How Secondary Conditions Might Indirectly Limit an Individual

The condition, weight problems, can reduce levels of independence or enjoyment of activities involving food. So, an individual may have agreed upon an IP objective involving a dietary plan that limits choices at meal times making eating less enjoyable for this person. The objective may impact independence by requiring someone to monitor the individual's consumption when food is available or by providing the consumer with support and assistance in grocery shopping and food preparation routines.

The condition, anger/outbursts, can reduce the number of opportunities a consumer might have to engage in an activity. This individual may be involved in a social activity that he/she enjoys, such as playing cards, but something leads the consumer to express anger or an outburst. Afterwards, other players involved in the card game are less willing to socially interact with the consumer or are even less willing to play cards with consumer at all. This can decrease the frequency and enjoyableness of the activity for the consumer.

The condition, depression, can reduce the number of times the individual participates in an activity. So, a depressed individual may go to a social function such as church less frequently than before he/she was depressed.

STRESS AND LIFE CHANGES

Finally, please complete the section on stress (pp.18-19). Research in various populations has shown that when an individual experiences significant life changes, he/she may be more at risk for poor health outcomes. Simply check the life changes the consumer has experienced in the last year. There is also space to write in changes not included on the list but that you feel were important to the consumer.
IS THE SECONDARY CONDITION A CONCERN FOR THE CONSUMER?

- Is the consumer concerned?
- Are you, the rater, concerned?
- Are friends, family, or other staff concerned?
- Is a health care professional concerned?
- Was it a concern discussed at the IP meeting?

On this questionnaire you will be asked to determine if a specific secondary condition has been a concern for the consumer during the past year. Next, you will estimate how much the condition limited the consumer during the past year. Finally, you will be asked to identify conditions that were on the consumer’s Individualized Plan (IP). Each item provides a brief description of a secondary disabling condition.

Observed secondary conditions

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>Weight Problems</th>
</tr>
</thead>
<tbody>
<tr>
<td>IP</td>
<td>People with Down Syndrome, muscular dystrophy, spina bifida, spastic cerebral palsy, and other developmental disabilities that cause decreased activity have at least a 50% risk of becoming obese. Also, an abnormal hypothalamic region of the brain may cause an individual to lack the feeling of satiation, as in the Prader-Willi Syndrome. Being underweight may also be a concern, and is sometimes associated with low muscle tone. You may observe low levels of activity or endurance, too much or too little time spent eating, mobility problems, or ill fitting/loose clothing.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>Physical Fitness and Conditioning Problems</th>
</tr>
</thead>
<tbody>
<tr>
<td>IP</td>
<td>Some people with disabilities find they are not able to do as much as they would like because they are out of shape. You may observe an individual become winded even on a short walk, taking frequent rest breaks, sweating and face reddening after minimal exertion, or avoiding physical activities. In most individuals, activity level is the cause and the cure; however, persons with cardiac conditions (often associated with Down Syndrome or Williams Syndrome) do have low exercise tolerance, and exercise programs for these individuals should be planned with a qualified physician.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>Personal Hygiene/ Appearance</th>
</tr>
</thead>
<tbody>
<tr>
<td>IP</td>
<td>Personal appearance and well-being can be altered by activities such as hand-washing, face washing, tooth brushing, deodorant use, bath/shower, hair washing, shaving, nail cleaning and clipping, etc. The absence of such activities can compromise health, self-esteem, job performance, or social interactions.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
HOW DOES THE SECONDARY CONDITION LIMIT THE CONSUMER?

(Dimensions of participation: Enjoyable, Skillful, Efficient, Frequent, & Independent)

<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Dental Hygiene</strong></td>
<td>People with developmental disabilities are shown to be at a greater risk for dental disease and malformations. Teeth may be missing, thinly enameled, abnormally shaped, or poorly cared for. This could lead to decay, a poorly fitting bite, tooth aches, or progressive tooth loss. You may also observe consistent bad breath, which can indicate tooth decay or infection. Poor dental hygiene can limit social interactions or eating pleasures.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Depression</strong></td>
<td>More than feeling blue. Symptoms include: extreme, long-term sadness; frequent or unexplained crying; loss of interest in personal appearance; less laughing or smiling than usual; withdrawal from favorite things, activities, or people; difficulty sleeping; weight loss or gain; change in behavior style (e.g., increase in anger/aggressive behavior); and/or comments about or actions towards suicide. Most depression in the developmental disabilities population is reactive depression, which responds well to situational interventions. Appropriate mental health professionals can help diagnose depression and develop a treatment plan.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Respiratory Problems</strong></td>
<td>Pneumonia and other respiratory tract infections can occur in disabled individuals. Symptoms of respiratory infections or problems can include difficulty in breathing and excessive, frequent, or prolonged coughing.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Injuries Due to Self Abuse</strong></td>
<td>Self injurious behavior can cause significant injury or can interfere with adaptive behaviors. Such behavior may be a result of dysfunctional reinforcement contingencies or may be an attempt to communicate discomfort, poor health, and/or pain. Individuals with ineffective communication systems or strategies may be at particular risk for this condition.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Is the Secondary Condition a Concern for the Consumer?

- **Is the consumer concerned?**
- **Are you, the rater, concerned?**
- **Are friends, family, or other staff concerned?**
- **Is a health care professional concerned?**
- **Was it a concern discussed at the IP meeting?**

#### Sleep Problems/ Disturbances

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
</table>
| **IP** | Difficulty falling asleep, difficulty staying awake during the day, or waking up frequently during regular sleep are all sleep disturbances. You may also observe sleep walking, frequent nightmares, or very loud snoring.

#### Fatigue

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
</table>
| **IP** | Fatigue is a tired (though not necessarily sleepy) feeling after minimal exertion. Fatigue after exertion is a common problem for individuals with congenital muscle disorders. You may observe low facial affect and motivation levels, slower rates of activity, more breaks, longer sleep periods, or naps.

#### Joint & Muscle Pain

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
</table>
| **IP** | This includes pain in specific muscle groups or joints. Individuals who must overuse a particular muscle group or those who must put too much strain on joints are at risk of developing joint and muscle pain. Individuals in wheelchairs, with significant spasticity, and/or mobility issues are also at risk. You may observe the individual favoring a particular limb, limping, displaying an odd gait, moving through a range of motion with difficulty, complaining directly to you, or standing up or sitting down with signs of unease.

#### Contractures

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
</table>
| **IP** | A contracture is a limitation in range of motion caused by shortening of the soft tissue around a joint (e.g., elbow, hip). This occurs when a joint cannot move frequently enough through its range of motion. You may observe decreased activity, pain indicators, or direct complaints.

#### Memory Problems

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
</table>
| **IP** | You may observe difficulty with short-term or long-term memory or a lack of awareness of skills and strategies needed to solve problems and perform tasks. Individuals may need continual prompting, may repeat questions when answers have been provided, may forget vital information such as bus schedules, or may frequently lose things. A change in memory capacity or emerging problems with memory can indicate side effects of medications, depression, or early dementia.
<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Balance Problems/ Dizziness</td>
<td>There is an impaired sense of direction and/or ability to coordinate movement. People may display a staggering gait, postural imbalance, clumsiness, or a strong sensation of lightheadedness following a change in position. This condition can be a sign of medication side effects, inner ear problems, or neurological disorders (e.g. stroke or infection of nervous system).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alcohol/Drug Abuse</td>
<td>Studies indicate drug/alcohol use is essentially the same in a population with disabilities as those without; however, conflicts with employment, family, or police as well as problems with the digestive system, interaction with prescribed drugs, seizure control, circulation, chronic infections, and mobility, arise more quickly and are worse for people with developmental disabilities. You may observe decreased job performance, mood swings, erratic eating schedules, oversleeping, and financial strain.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bladder Dysfunction</td>
<td>Persons with poor muscle function or lack of sensation in the area of the bladder are at risk for bladder dysfunction. You may observe evidence of incontinence, bladder or kidney stones, kidney problems, leakage, urine backup, and associated problems. The individual may complain of a burning sensation during urination or abdominal pain. Blood in or discoloration of urine and/or foul smelling urine may also be observed.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bowel Dysfunction</td>
<td>Diarrhea, constipation, &quot;accidents,&quot; bowel impactions, 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. Persons who are dependent on others to maintain a recommended bowel program are also at risk for this condition.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
IS THE SECONDARY CONDITION A CONCERN FOR THE CONSUMER?

- Is the consumer concerned?
- Are you, the rater, concerned?
- Are friends, family, or other staff concerned?
- Is a health care professional concerned?
- Was it a concern discussed at the IP meeting?

0 1 2 3 Persistence
Problems/ Low Frustration Tolerance

Long term enablement of parents and care providers or repeated failures due to learning or other difficulties may lead to feelings of incompetence or helplessness in adults with developmental disabilities. You may observe an individual consistently giving up on tasks and goals after exhibiting only minimal frustration. The individual may express his/her frustration with negative facial affect associated with anger, sadness or withdrawal; with clenched fists or rigid body posture; or with negative statements about his/her own abilities.

0 1 2 3 Communication
Difficulties

This includes difficulty talking due to a ventilator, speech problems and disorders, impaired muscle control around the mouth, and other problems communicating with others. It can also be difficult to communicate when others (peers, family, health care providers, and staff) are not familiar with the consumer's mode of communication and/or behavioral cues. This lack of understanding can result in frustration and acting-out behaviors. Finally, visually impaired persons and persons with reading disorders may be print handicapped, while others cannot turn pages or hold books and magazines. Still others find it difficult to write or type because of their disability.

0 1 2 3 Vision Problems

Significant loss of ability to see (e.g., loss of acuity or field of vision) including blindness. You may observe the individual squinting at printed matter or holding it at a distance, bumping into or tripping over objects, or closing eyes for prolonged periods of time. Individuals who have been prescribed visual aids (e.g. glasses, contacts), but who are not using them as needed, will probably experience limitation as a result of this condition.

0 1 2 3 Hearing Problems

The criteria for hearing impairment is "difficulty with hearing in general or with hearing particular kinds of sounds." The individual may not respond to voices or distinct noises, may listen to music or TV at loud volumes, or may talk too loudly or softly given certain situations.
**HOW DOES THE SECONDARY CONDITION LIMIT THE CONSUMER?**

(Dimensions of participation: Enjoyable, Skillful, Efficient, Frequent, & Independent)

0 = No limitation
1 = Mild/infrequent limitation of activity (limits activity 1 to 5 hours per week)
2 = Moderate/occasional limitation of activity (limits activity 6 to 10 hours per week)
3 = Significant/chronic problem (limits activity 11 or more hours per week)

---

0 1 2 3  | Care-related Injuries to Consumer  
---  | ---  
0 | 1 | 2 | 3  

When providing personal care, some injuries to the consumer may result (e.g. cuts or bruises). These types of injuries occur normally and are not signs of abuse.

0 1 2 3  | Care-related Injuries to Others  
---  | ---  
0 | 1 | 2 | 3  

Injuries to others, such as a sprained back, can occur in the process of providing care. These types of injuries occur normally and are not the result of abuse.

0 1 2 3  | Problems with Mobility  
---  | ---  
0 | 1 | 2 | 3  

Many individuals with physical disabilities are troubled by difficulty with getting around, due to a loss of strength or muscle control. Individuals with cerebral palsy, spinal cord problems, or central nervous system problems are at risk for this condition. (Note: If you rate this as a "1," a "2," or a "3," then you should also complete the following supplementary secondary conditions.)

---

**Supplementary secondary conditions**

If the consumer has a mobility impairment, please complete the following section. If the consumer does not have a mobility impairment, proceed to page 16.

0 1 2 3  | Access Problems  
---  | ---  
0 | 1 | 2 | 3  

Access problems in the environment, such as lack of curb cuts or accessible buildings and restrooms, can pose an obstacle to functioning independently. When supports (e.g. PCA, motorized wheelchair, and communication technology) are identified as being facilitative of independence for an individual but are unavailable (unaccessible) across all settings, then he/she is also experiencing access problems.

0 1 2 3  | Equipment Failures  
---  | ---  
0 | 1 | 2 | 3  

Equipment failures, such as a broken walker or brace, can limit independence by increasing the difficulty or prohibiting the completion of many desired activities.
IS THE SECONDARY CONDITION A CONCERN FOR THE CONSUMER?

→ Is the consumer concerned?
→ Are you, the rater, concerned?
→ Are friends, family, or other staff concerned?
→ Is a health care professional concerned?
→ Was it a concern discussed at the IP meeting?

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 Equipment-related Injuries to Yourself The use of adaptive equipment can lead to injuries (e.g., injuries to one's underarms from poorly fitting crutches) that can limit an individual's completion of desired activities.

0 1 2 3 Equipment-related Injuries to Others The use of adaptive equipment can lead to injuries to others, such as injuries received moving heavy adaptive equipment.

0 1 2 3 Injuries Due to Accidents/Seizures Learning or physical difficulties may lead to accidents resulting in injury. A seizure may place an individual at risk for an accident as well.

0 1 2 3 Instability of neck (Atlanto-axial Dislocation) This is a progressive condition involving greater than normal mobility of the upper two cervical vertebrae. People with this condition are susceptible to serious spinal cord injury if their necks are severely bent or jarred. Almost one sixth of all individuals with Down Syndrome are said to be affected by this condition.

0 1 2 3 Scoliosis (Kyphosis/Lordosis) These three terms refer to abnormal curvatures of the spine. Scoliosis is the curvature of the spine sideways; Lordosis is the forward curvature of the spine; Kyphosis is the curvature of the upper back known as "hunchback." Persons with cerebral palsy or spinal deformities are at risk of these because of improper sitting positions, muscle imbalance and/or spasticity, or paralysis.

0 1 2 3 Injuries Due to Loss of Sensation Many people with disabilities involving loss of sensation (e.g., spina bifida, diabetes) report injuries because they cannot feel pain in some areas (e.g., frostbite, burns from sitting too close to heater or fire).
Possible or identified medical secondary conditions

These are conditions that have been formally diagnosed by an appropriate health care professional or conditions that you may be aware of or suspect are affecting the consumer's overall health and independence.

0 1 2 3  Gastrointestinal Dysfunction

The nutritional status of an individual may be affected by gagging, vomiting, or rumination (swallowing, vomiting, re-chewing, and re-swallowing). These may be esophageal dysfunctions that can lower a person's nutritional status as well as their sociability during meal times. SUCH PROBLEMS MAY BE LIFE-THREATENING. Frequent or consistent gagging or coughing during mealtimes are indications that this condition should be investigated. Coughing and gagging should NOT be accepted as part of the mealtime routine; these are indicators that continued feeding will jeopardize an individual's safety.

0 1 2 3  Side Effects From Medications

Several medications prescribed for various problems may produce unwanted medication side effects. For example, you may observe drooling, loss of appetite, shaking body or hands, or rocking motion. A physician should be consulted about alternative treatment plans.

0 1 2 3  Allergies and Allergic Reactions

The symptoms can range from mild rashes to puffy, red eyes to life threatening anaphylactic shock. People with spina bifida are at an increased risk for having latex sensitivity because of early and frequent surgical procedures associated with the disorder. A latex reaction can be caused by cross-reactivity of foods such as bananas, avocados, water chestnuts, and other fruits.

0 1 2 3  Arthritis

Arthritis results from inflammation of the joints, making movement both difficult and painful. Cold weather and stress can make this condition worse. You may observe contracted joints, swelling around the joints, difficulty in moving, or pain.
**IS THE SECONDARY CONDITION A CONCERN FOR THE CONSUMER?**

- Is the consumer concerned?
- Are you, the rater, concerned?
- Are friends, family, or other staff concerned?
- Is a health care professional concerned?
- Was it a concern discussed at the IP meeting?

<table>
<thead>
<tr>
<th>Code</th>
<th>Condition</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 Diabetes</td>
<td>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. This condition can be diagnosed and is easily managed.</td>
<td></td>
</tr>
<tr>
<td>0 1 2 3 Sexually Transmitted Disease</td>
<td>Individuals engaged in sexual intercourse are at risk for diseases such as chlamydia, gonorrhea, genital warts or herpes, syphilis, and AIDS. An accurate record of sexual history may be difficult to obtain, but you may observe avoidance of or painful urinations, foul odors, or excessive scratching of genital regions.</td>
<td></td>
</tr>
<tr>
<td>0 1 2 3 Urinary Tract Infections</td>
<td>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 lacking pain sensation may be unaware of the infection. The most common causes of UTI's are poor hygiene and sexual intercourse.</td>
<td></td>
</tr>
<tr>
<td>0 1 2 3 Osteoporosis</td>
<td>This is a wasting of bone. It may cause pain, can lead to fractures, and predisposes individuals to developing urinary tract stones. Any individual with a disability 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.</td>
<td></td>
</tr>
<tr>
<td>0 1 2 3 Heterotopic Bone Ossification</td>
<td>This is an overgrowth of bone, often occurring after a fracture. Early signs include a loss in range of motion, local swelling, and warmth at the area to the touch. It must be diagnosed by a physician. People with chronic repetitive motion activities are at risk for this condition.</td>
<td></td>
</tr>
<tr>
<td>0 1 2 3 Cardiovascular (Heart)/Circulatory Problems</td>
<td>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, veins, or feet, or the occurrence of blood clots.</td>
<td></td>
</tr>
<tr>
<td>0 1 2 3 Postural Hypotension</td>
<td>This involves a strong sensation of lightheadedness following a change in position. It is caused by a sudden drop in blood pressure. You may observe frequent dizzy spells. This can be a common side effect of some medications.</td>
<td></td>
</tr>
<tr>
<td>0 1 2 3 Nutritional Deficits</td>
<td>This is when the taking in of food and drink does not provide required nourishment for proper body functioning and maintenance of health. Problems for taking in nutrients may occur during eating, digestion, absorption (nutrients into blood), assimilation (nutrients into living cells), or excretion. Long term undernutrition may badly affect immune response, respiratory muscle strength, peripheral circulation, attention span and learning, mood, motivation, and energy.</td>
<td></td>
</tr>
</tbody>
</table>
This next section concerns behaviors or life changes that may indicate that the consumer is experiencing stress. Which of the following events were experienced by the consumer during the past two years?

- Death of a close family member
- Death of a close friend or housemate
- Change in residence
- Gaining a new roommate or housemate
- Changing to different line of work
- Troubles with boss
- Outstanding personal achievement
- Major change in responsibilities at work (e.g. promotion, demotion, lateral transfer)
- Major change in working hours or conditions
- Changing to a new school
- Major change in sleeping habits (a lot more or a lot less sleep, or change in time of day when asleep)
- Major change in eating habits (a lot more or a lot less food intake, or very different meal hours or surroundings)
- Revision of personal habits (dress, manners, associations, etc.)
- Minor violations of the law (e.g. traffic tickets, jay walking, disturbing the peace, etc.)
- Detention in jail
- Pregnancy
- Major change in health or behavior of a housemate
- Major change in number of family get-togethers (a lot more or a lot less than usual)
- Major changes in financial state (e.g. a lot worse off or a lot better off than usual)
- Gaining a new family member (e.g. through birth, adoption, etc.)
- Housemate moving out
- Major change in church activities (a lot more or a lot less than usual)
- Being fired from work
- Major change in the number of arguments with housemate (either a lot more or a lot less than usual regarding personal habits, etc.)
- Major change in usual type and/or amount of recreation
- Major personal injury
- Major change in social activities (e.g. clubs, dancing, movies, visiting, etc.)
- Major change in living conditions (e.g. building a new home, remodeling, deterioration of home or neighborhood)
- Retirement from work
- Vacation
- Beginning or ceasing formal schooling
- Change or disruption in normal care of the individual
- Change in personal care attendant or direct care staff member
- Change in transportation (including a bus route, or van schedule)
- Change in health care provider (e.g. doctor, nurse, therapist, or dentist)
- Change in Case Manager
- Other Major Life Changes? Specify: ___________________________
APPENDIX D: INTER-RATER RELIABILITY FOR THE HEALTH AND SECONDARY CONDITIONS SURVEILLANCE INSTRUMENT FOR ADULTS WITH DEVELOPMENTAL DISABILITIES

Eleven dual survey reports were available for the assessment of inter-rater reliability of the measures used in the present study. A second kappa for the frequency of secondary conditions is being presented here as an alternative to the corrected chance agreement reported in the method section of this dissertation. It was calculated in response to a suggestion of a primary constituent, who reported that an estimation of no or mild limitation due a secondary condition may lead a direct care provider to monitor the condition, but not to implement some kind of treatment plan, whereas an estimation of moderate or severe limitation would warrant a treatment plan. The calculation of this kappa counted ratings of no limitation and/or mild limitation by both raters as an agreement, ratings of moderate and/or severe limitation as an agreement, and a rating of no or mild limitation by one rater and a rating of moderate or severe limitation by the other rater as a disagreement. The resulting kappa implied moderate agreement ($\kappa = .56$).

Interestingly, both kappas for the frequency of secondary conditions (i.e., the one presented in the method section of this dissertation and the one presented here) may be conceived of as alternative, incrementally weighted kappas to those reported to reflect the corrected chance agreement on the ratings of limitation, which contribute to the sum of severity summary score.

This additional inter-rater reliability index suggests several issues for future research. First, the suggestion to consider an alternative conceptualization of the frequency of secondary conditions prompted an examination of the reliability of the
traditional summary score in comparison with the alternative score. Indeed, summarizing
the occurrence-nonoccurrence of secondary conditions in this manner resulted in better
reliability (i.e., improvement from .41 to .56). Second, the current Health and Secondary
Conditions Surveillance Instrument for Adults with Developmental Disabilities
(HSCSIADD) uses a response scale that was developed for self-report of limitation
associated with secondary conditions (i.e., persons with mobility impairments). Future
revisions of the HSCSIADD could pilot test alternative scales that might elicit proxy
raters’ estimations of limitation associated with secondary conditions more reliably. Third,
revisions could be made in the completion protocol. For example, a multi-disciplinary
team, such as the Individual Plan team, might work with a consumer to estimate the
amount of limitation associated with secondary conditions more reliably than would a
single direct care provider. Finally, methods for including consumers more fully in the
communication and estimation of the limitation they experience due to secondary
conditions must be improved. The differences between proxy and self-reports are being
well described in current literature (e.g., Goode & Hogg, 1994; Todorov & Kirchner,
2000), and in some cases, tend to reflect a perception of greater disability associated
limitation on the part of proxy raters when compared to ratings of persons with the
disabling condition (e.g., Andersen, Fitch, McLendon, & Meyers, 2000). The differences
in the predictive utility of self-rated health and physician rated health have been described
and continue to be an ongoing issue in health psychology (e.g., Hooker & Siegler, 1992;
Schoenfeld, Malmrose, Blazer, Gold, & Seeman, 1994). Little is known about the
predictive utility of proxy-rated health. This issue warrants further research, particularly
when one considers potential mechanisms of health promotion that may be affected by the perceptions of proxies who are direct care providers. Finally, alternative remedies to proxy raters are needed to address the issues of low reliability regarding the responding of persons with cognitive impairments (e.g., DeBettignies, Mahurin, & Pirozzolo, 1990). The importance of measuring self-rated health as a screening devise for persons at much greater risk for outcomes such as mortality (e.g., Shoenfeld et al., 1994) cannot be disregarded as potentially useful in this population because of methodological issues.

In addition to the calculation of a reliability index for the alternative frequency of secondary conditions score, four individual agreement estimates were calculated for the severity ratings of a subset of mobility-related secondary conditions (nine conditions) and a subset of the remaining conditions; they were calculated in addition to the reliability indices reflecting agreement on all 44 secondary condition items (reported in the method section of this dissertation). These estimates were moderate (κ = .54) and fair (κ = .30) levels of agreement, respectively. The incrementally weighted kappas for ratings corresponding to the two subsets of secondary conditions represented substantial (κw = .77) and moderate (κ = .46) levels of agreement, respectively. The higher reliability found for the section on mobility-related secondary conditions was consistent with the pattern of reliability found recently in a study of the agreement between ratings on the US Census 2000 disability items independently given to individuals with a disability and a proxy (i.e., spouse, relative, friend, or health care professionals; Andersen et al., 2000). The highest reported kappas for this study were for the two Census items associated with mobility impairment. Potentially, the issues surrounding mobility impairment are relatively well-
defined and associated limitations are clear amongst persons associated, either directly or indirectly, with these impairments. Efforts are needed to improve items so that they reflect respondents, conceptualizations of disabilities, secondary conditions, and limitation (Andersen et al., 2000). Implications of the pattern of findings from the present study include the need for measurement refinements. A revision specific to the HSCISADD may be to reorganize the secondary condition items into impairment categories (i.e., WHO, 1999). Raters may be more likely to agree upon the discrete secondary condition associated with the observed limitation if similar items (e.g., joint and muscle pain, arthritis, osteoporosis, contractures, and heterotopic bone ossification) are placed together as opposed to being located in different sections of the instrument. Ratings of overlapping items may be biased by individual response styles in the current format. Proximity of like items could facilitate finer discrimination among the items by all raters.

In summary, an essential component of future research must address issues of measurement. Some of these issues are the variability in definitions of disability and secondary conditions, the difficulties measuring limitation and participation across dimensions and contexts, and the effectiveness of response supports for persons with cognitive disabilities. Given that so many levels of planning are affected by them, the validity and reliability of assessments of the prevalence and incidence of disabilities and secondary conditions must be improved.
APPENDIX E: DETAILED DESCRIPTION OF REGRESSION ANALYSES

Details of the univariate analysis that were not presented in results section of the dissertation are included in this appendix. Additionally, complete descriptions of the regression models derived from the transformed data are included.

The univariate perspective for assessing normality examines the distribution of data for each variable in comparison with the normal curve. Z test statistics based on skewness values were calculated for both predictors and both dependent variables to be used in the regression analyses, and the Kolmogorov-Smirnov tests of normality were also performed. These indicated nonnormal distributions of data for each variable (i.e., significant at the .05 probability level). Histograms and normal probability plots of each predictor and dependent variable indicated that their respective distributions were positively skewed. Upon further examination of each variable, box as well as stem and leaf plots identified three to eight cases as being an extreme data point or an outlier. All but four of these cases also had z scores that were equal to or exceeded ± 2.5. Upon closer examination, the data for these cases were considered representative for segments of this population, and therefore were not excluded from the analyses.

From the multivariate perspective, the initial variates resulting from the regressions of the frequency of secondary conditions and the sum of severity ratings associated with

1 Given their dependence on distributions of cumulative percentiles (i.e, quartile ranges), the thresholds for the two types of plots were slightly lower than the z score thresholds. Because of the positively skewed nature of each variable's data distributions, these thresholds may be more appropriate than those of the z scores, which are based on normal distribution.
secondary conditions on age and life changes yielded residuals that, when plotted in a histogram, were positively skewed relative to the normal distribution. In order to assess homoscedasticity, the studentized residuals from each regression model were plotted against each model's predicted criterion values. Resulting scatterplot patterns approximated the null plot, and thus indicated that the data were homoscedastic. As a result of the univariate examinations of the data, the only remedies applied to the data sets were to achieve normality. Natural logs of age normalized this distribution. Square root transformations of the frequency of secondary conditions, the sum of severity ratings associated with secondary conditions, and the total life changes normalized the data distributions for the individual variables. Univariate analyses of the transformed data indicated that age, total life changes, frequency of secondary conditions, and sum of severity ratings associated with secondary conditions approximated normality, though there were mixed indications in this regard. Z test statistics based on skewness values were nonsignificant for all variables (i.e., indicated normality). Histograms and normal probability plots of each dependent variable approximated normality although those depicting the distributions of age and total life changes were less normal and indicated a slight negative skew in the distributions. Finally, the Kolmogorov-Smirnov tests of normality were again significant (i.e., significant at the .05 probability level) for all variables, thus suggesting that there was still some departure from normality.

2 Natural logs were not taken because: 1. there were seven, seven and fifteen zero values in the data sets for the three variables, respectively; 2. the natural logs of the data points plus an additional small constant (i.e., .10) overcorrected the distributions for normality yielding negatively skewed data sets.
Importantly, the subsequent regressions that analyzed relationships of the transformed data resulted in variates yielding studentized residuals that were normally distributed. Because the square root transformations render the interpretations of these variates less intuitive, the resulting regression models were compared to models utilizing the nontransformed data. Since the models were similar, those derived from nontransformed data were presented in the results section of this dissertation. The models of transformed data are presented here to allow interested readers to compare the pairs of models.

Table E1 describes the regression models derived from the transformed data. Again, total life changes and age were included as predictors of: (Model 1') the frequency of secondary conditions experienced by consumers of state DDP ($SC_{frequency}$) \[= b_0 + b_1 \text{ (Natural log of Age)} + b_2 (TOT \text{ LC})^{1/2} + \varepsilon \] and (Model 2') the sum of severity ratings associated with secondary conditions experienced by consumers of state DDP ($SC_{severity}$) \[= b_0 + b_1 \text{ (Natural log of Age)} + b_2 (TOT \text{ LC})^{1/2} + \varepsilon. \]

For Model 1' ($R^2 = .06, F(2, 254) = 8.35, p < .05$), age was a significant predictor of $SC_{frequency}$ ($b_1 = .76, \beta_1 = .23, t(255) = 3.74, p < .05$). In Model 1', age (transformed) uniquely accounted for 5.2% of the variance in the transformed criterion variable, frequency of secondary conditions. Model 1 predicts that an increase of one unit in the natural log of age is related to an increase of .76 units in the square root of frequency of secondary conditions. For 95% of the sample, an increase of one unit in age (transformed) is related to an increase in units of the frequency of secondary conditions (transformed) ranging from .36 to 1.16. In Model 1', total life changes was a significant predictor of.
SC_{frequency} (b_2 = .14, \beta_2 = .12; t(255) = 2.01, p < .05). It uniquely accounted for 1.5% of the variance in the SC_{frequency}. From Model 1', one may surmise that one unit change in the square root of total life change predicts a .14 unit change in the square root of SC_{frequency}.

Taking into account the confidence interval (CI), one may predict that with one unit increase in the total life changes (transformed), 95% of the sample will experience an increase ranging from .00 to .28 units in the frequency of secondary conditions (transformed).

Table E1

Summary of Regression Models Predicting the Frequency of Secondary Conditions and the Sum of Severity Ratings Associated with Secondary Experienced by Adult Consumers of DHHSDDP.

<table>
<thead>
<tr>
<th>Variable</th>
<th>R^2</th>
<th>F (2,254)</th>
<th>B</th>
<th>SE B</th>
<th>\beta</th>
<th>t (255)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Model 1'</td>
<td>.06</td>
<td>8.35***</td>
<td>.76</td>
<td>.20</td>
<td>.23</td>
<td>3.74***</td>
</tr>
<tr>
<td>Consumer's Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Life Changes</td>
<td></td>
<td></td>
<td>.14</td>
<td>.07</td>
<td>.12</td>
<td>2.014*</td>
</tr>
<tr>
<td>Model 2'</td>
<td>.05</td>
<td>6.44**</td>
<td>.97</td>
<td>.30</td>
<td>.20</td>
<td>3.26**</td>
</tr>
<tr>
<td>Consumer's Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Life Changes</td>
<td></td>
<td></td>
<td>.19</td>
<td>.10</td>
<td>.12</td>
<td>1.89</td>
</tr>
</tbody>
</table>

Note: *p < .05; **p < .01; ***p < .001.
For Model 2' (R² = .05, F(2, 254) = 6.44, p < .05), the natural log of age was a significant predictor of SCseverity (β₁ = .97, β₁ = .20, t(255) = 3.26, p < .05). In Model 2, age (transformed) uniquely accounted for 4.0% of the variance in the transformed criterion variable, the SCseverity. Model 2' predicts that an increase of one unit in the natural log of age is related to an increase of .96 units in the square root of SCseverity (CI = .38 to 1.55 units in the square root of SCseverity). In Model 2', the square root of total life changes was not a significant predictor of the square root of SCseverity (β₂ = .19; β₂ = .12, t(255) = 1.89, p = .07). Although there was a trend toward significance, total life changes (transformed) uniquely accounted for an nonsignificant amount of the variance (1.2%) in the square root of SCseverity. Again, because the patterns of findings from analyses conducted with transformed and with nontransformed data were similar, it was deemed appropriate to present interpretations of the latter models in the results section of this paper, specifically because they were more intuitive.
APPENDIX F: VALIDATION OF MODELS 1 AND 2:
REGRESSION ANALYSES OF DATA FROM AN INDEPENDENT SAMPLE OF ADULTS WITH DEVELOPMENTAL DISABILITIES FOR WHOM A SECONDARY CONDITIONS SURVEILLANCE INSTRUMENT WAS COMPLETED

Method

Participants

An independent second sample of adult consumers of the Montana State Department of Health and Human Services Developmental Disabilities Programs (DHHSDDP) provided the data used to validate the regression models of the present study. In the Fall of 1999, health surveillance instruments were sent to 1,925 consumers (1,572 were consuming services from at least one private service corporation and 353 were receiving DHHSDDP waiting list services). The survey return rate was 39% (N =749). One hundred and two individuals were described previously in the main sample of the present study. Their data were excluded from validation analyses of the present study. The independent sample included 647 adults.

In the validation sample, individuals ranged in age from 16 to 93 (M = 43.34; SD =14.62). Age did not vary significantly between the main study sample and the validation sample (t(557.7) = 0.25, p > .05). In addition, analyses of gender data from the main study sample and the validation sample indicated that the respective distributions were not statistically different (χ^2 (1, N = 904) = .21, p >.05). There were significant differences in the distributions of participants across urban (i.e., metropolitan counties with at least a 100,000 population size, at least), semi-rural (i.e., non-metropolitan counties economically
adjacent to metropolitan county, which implies that non-metropolitan county residents commute to the metropolitan county) and remote-rural (i.e., non-metropolitan counties non-adjacent to metropolitan county) counties in Montana, as defined by USDA Urban-Rural continuum code or "Beale code" ($\chi^2 (2, N = 880) = 11.89, p < .05$; McGranahan, Hession, Hines, & Jordan, 1986). Specifically, there were more participants in the validation sample who resided in semi-rural counties; however, only four percent of the validation sample resided in such counties whereas no participants in the main study sample resided in this type of county. Additionally, proportions of the validation sample residing in remote-rural counties and in urban counties were similar to the proportions of such residents in the main study sample. The distributions of participants from each sample across the two broad categories of residential arrangements were statistically different ($\chi^2 (1, N = 833) = 42.48, p < .05$). Compared to the main sample of the present study, almost three times the percentage of individuals in the validation sample lived in either an independent residence or with a family (adopted or natural; 12% versus 30%), and sixty-six percent of the validation sample resided in supported living arrangements (i.e., supported independent living arrangement, intensive care group home, non-intensive group home, or intermediate care facility (ICF-MR)). Current Inventory for Client and Agency Planning (ICAP) data, which are collected annually for persons served by the Montana DDP, are not yet available for participants in the validation sample. However, the validation sample did have data on primary disability, which indicated that ninety-three percent of the sample identified mental retardation as their primary impairment. The proportion of persons identifying mental retardation as their primary disability in the
validation sample did not differ significantly from the comparative proportion in the validation sample ($\chi^2 (1, N = 895) = .27, p >.05$). In comparison to the descriptor generated from the ICAP data available for adult consumers of Montana HHSDDDP (as of January 15, 1998), the validation sample was representative of consumers of state developmental disability adult service programs in terms of age, gender, and primary disability.

**Measures**

Direct care providers acted as proxy raters for participants in the validation sample. They completed a revised version of the Health and Secondary Conditions Surveillance Instrument for Adults with Developmental Disabilities. It was very similar to the HSCSIADD described in the Method section of the present study. It included an assessment of secondary conditions, life events, demographic information, overall health and independence, and a health care-utilization and accessibility measure. The major changes to this version were the addition of cancer as a secondary condition item and an expansion of the health care-utilization and accessibility section. There were also two life changes added to the inventory (i.e., loss of a pet and change in medication). The inventory format was revised from a single checklist to six subsets of checklists: Family (4 items), Home (13 items), Work/School (8 items), Lifestyle (9 items), Health (4 items), and Other (1 item). Summary scores for the validation phase were derived as described in the main text of the present study. Again the summary scores of the dependent variables reflect completion criteria of 80% (i.e., descriptors for cases with less than 20% missing data). Fifty-five cases of the validation sample did not meet this criteria. In the validation
sample, internal consistency reliability for the sum of severity ratings was acceptable, with Cronbach’s alpha equal to .88.

Results

Descriptive Statistics

Descriptive statistics, including means and standard deviations by gender and correlations of the dependent variables with age can be found in Table F1. Student t-ratios revealed significant variation between genders on the frequency of secondary conditions, but there were no differences between genders on the sum of severity associated with secondary conditions. Correlation analyses revealed that age was significantly related to the frequency of secondary conditions and to the sum of severity ratings. These low to moderate correlations suggest that as age increases, there is a related increase in the frequency of secondary conditions experienced by consumers and in the sum of severity ratings of limitation associated with secondary conditions. Given these findings, both age and gender were controlled for in the regression analysis testing the relationship between life changes and the frequency of secondary conditions, and age was controlled for in the regression analysis testing the relationship between life changes and the sum of severity ratings associated with secondary conditions. Other traditional demographic variables such as SES and level of education were not available in the validation data set.

Life Changes and the Experience of Secondary Conditions

To test the hypothesis that there is a significant and positive, linear relationship between scores on the LCIADD (TOT LC) and the frequency of secondary conditions experienced as limiting (SC_{frequency}), SC_{frequency} was regressed onto life changes, age, and
Table F1

**Means and Standard Deviations by Gender and Correlations Between Age, Frequency of Secondary Conditions, and Sum of Severity Ratings Associated with Secondary Conditions.**

<table>
<thead>
<tr>
<th>Measure</th>
<th>Males</th>
<th>Females</th>
<th>r&lt;sub&gt;age&lt;/sub&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequency of Secondary Conditions</td>
<td>6.72 ††</td>
<td>8.19</td>
<td>6.94</td>
</tr>
<tr>
<td>Sum of Severity Ratings</td>
<td>10.97</td>
<td>12.85</td>
<td>12.81</td>
</tr>
</tbody>
</table>

**Note.** N = 584; † Pearson product-moment correlation coefficients (two-tailed); **p<.001; †† t (511.12) = -2.80, p < .05.

gender. To test the hypothesis asserting that there is a linear relationship between TOT LC and the sum of severity limitation ratings associated with secondary conditions (SC<sub>severity</sub>), SC<sub>severity</sub> was regressed onto the life changes and age.

Univariate and multivariate examinations of the validation sample data indicated that the data were homoscedastic, and analyses did not have to address issues of multicollinearity, outliers or curvilinearity. Nonnormal, positively skewed distributions for the two independent and the two dependent variables were indicated, however. Given these considerations, remedies to address the assumption of normality were applied to the data sets. While the resulting models were more valid, the relative equivalence of regression coefficients allowed interpretations to be formed from models derived from the nontransformed data, which were more intuitive.
Table F2 describes the regression models predicting: (Model 1) the frequency of secondary conditions experienced by consumers of state DDP \( (SC_{\text{frequency}}) = b_0 + b_1 \text{ (Age)} + b_2 \text{ (Gender)} + b_3 \text{ (TOT LC)} + \epsilon \) and (Model 2) the sum of severity ratings associated with secondary conditions experienced by consumers of state DDP \( (SC_{\text{severity}}) = b_0 + b_1 \text{ (Age)} + b_2 \text{ (TOT LC)} + \epsilon \).

For Model 1 \( (R^2 = .21, F(3, 553) = 49.68, p < .05) \), age was a significant predictor of \( SC_{\text{frequency}} \) \( (b_1 = .11, \beta_1 = .26, t(555) = 6.76, p < .05) \). In Model 1, age uniquely accounted for 6.5% of the variance in the criterion variable, frequency of secondary conditions. Model 1 predicts that an increase in age of one year is related to an increase of .11 units in the frequency of secondary conditions. For 95% of the sample, an increase in age of one year is related to an increase in units of the frequency of secondary conditions ranging from .08 to .14. Gender was also a significant predictor of \( SC_{\text{frequency}} \) \( (b_2 = 1.40, \beta_2 = .11, t(555) = 2.89, p < .05) \). In Model 1, total life changes was a significant predictor of \( SC_{\text{frequency}} \) \( (b_3 = .66, \beta_3 = .37, t(555) = 9.77, p < .05) \). It uniquely accounted for 13.6% of the variance in the \( SC_{\text{frequency}} \). From Model 1, one may surmise that one unit change in life change predicts a .66 unit change in \( SC_{\text{frequency}} \). Taking into account the confidence interval (CI), one may predict that with one unit increase in the total life changes, 95% of the sample will experience an increase ranging from .53 to .79 units in the frequency of secondary conditions.

For Model 2 \( (R^2 = .16, F(2, 557) = 51.60, p < .05) \), age was a significant predictor of \( SC_{\text{severity}} \) \( (b_1 = .19, \beta_1 = .23, t(559) = 5.95, p < .05) \). In Model 2, age uniquely
accounted for 5.4% of the variance in the criterion variable, the SC_{severity}. Model 2 predicts that an increase of one year in age is related to an increase of .19 units in the SC_{severity} (CI = .13 to .25 units in frequency of secondary conditions). In Model 2, the predictor variable, TOT LC, was shown to have a significant t-ratio associated with its slope parameter (i.e., \( b_2 = 1.11, \beta_2 = .33, t(558) = 8.48, p < .05 \)). The total life changes experienced uniquely accounted for 10.9% of the variance in the SC_{severity}. Taking into account the CI, one may predict that with one unit increase in the total life changes, 95% of the sample will experience an increase ranging from .85 to 1.37 units in the SC_{severity}.

Table F2

Summary of Regression Analyses: Predicting the Frequency of Secondary Conditions and the Sum of Severity Ratings Associated with Secondary Conditions Experienced by Adult Consumers of Montana DDP (N = 559).

<table>
<thead>
<tr>
<th>Variable</th>
<th>( R^2 )</th>
<th>( F )</th>
<th>B</th>
<th>SE B</th>
<th>( \beta )</th>
<th>( t (580) )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Model 1 (Predicting SC_{frequency})</td>
<td>.21</td>
<td>49.68***</td>
<td>.11</td>
<td>.02</td>
<td>.26</td>
<td>6.76***</td>
</tr>
<tr>
<td>Consumer’s Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td>1.40</td>
<td>.49</td>
<td>.11</td>
<td>2.89**</td>
</tr>
<tr>
<td>Total Life Changes</td>
<td></td>
<td></td>
<td>.66</td>
<td>.07</td>
<td>.37</td>
<td>9.77***</td>
</tr>
<tr>
<td>Model 2 (Predicting SC_{severity})</td>
<td>.16</td>
<td>51.59***</td>
<td>.19</td>
<td>.03</td>
<td>.23</td>
<td>5.95***</td>
</tr>
<tr>
<td>Consumer’s Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Life Changes</td>
<td></td>
<td></td>
<td>1.11</td>
<td>.13</td>
<td>.33</td>
<td>8.48***</td>
</tr>
</tbody>
</table>

Note: *p < .05; **p < .01; ***p < .001; SC_{frequency} = Frequency of Secondary Conditions; SC_{severity} = Sum of Severity Ratings Associated with Secondary Conditions.
Discussion

The results of the validation regression analyses were fairly consistent with patterns of prediction described for the main sample of this study. Two main differences were the inclusion of gender as an important predictor to be controlled for in the validation model predicting the frequency of secondary conditions experienced as limiting and the finding of significance for the relationship between total life changes and sum of severity ratings associated with secondary conditions. An interpretation for both differences is that the power available in the validation sample was enough to produce the effect sizes associated with gender and total life changes’ partial correlation coefficients while the power available in the main sample of this study was not. Hence, the lack of findings regarding these relationships in the analyses of the main study could be interpreted as Type II errors. Other explanations for these differences could be associated with revisions in the surveillance instrument. The inclusion of supplementary secondary conditions among the observed and medically related secondary conditions may have eased the completion of the secondary condition items. Similarly, the re-formatting of the life changes inventory (i.e., six subsets of life changes) could have facilitated the completion process for this inventory. Additionally, the inclusion of the two new life changes, particularly "change in medication," may have improved the inventory’s ability to predict health-related changes. The larger coefficients of determination and regression coefficients for total life changes associated with the validation models may be explained by such revisions as well. Finally, education of state corporation personnel on issues of secondary conditions and life changes, which occurred between the main study’s survey
and the validation survey, may have increased the common understanding of these issues. As a result, the reliability of the instrument may have increased (although ratings from dual respondents were not available for this sample), and thus, the variability due to measurement error may have been reduced.