Final Report: Idaho Real Choices System Change Project

September 30, 2006

For more information find us on the web at http://www.isu.edu/irh or e-mail us at realchoices@isu.edu.
Institute of Rural Health
Idaho State University
Pocatello, ID 83209
208-282-4436

FUNDING CREDIT & AUTHORS & CITATION

Funding Credit

This document was developed, in part, under Grants No. P-91537/0 and No.11-P-92045/0 from the U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services. The statements contained in this report are solely those of the authors and do not necessarily reflect the views or policies of the Centers for Medicare & Medicaid Services. The contractor assumes responsibility for the accuracy and completeness of the contained information.

Authorship

This report was prepared by the Real Choices Research Team, Institute of Rural Health, Idaho State University. This document was developed, in part, under Grants No. P-91537/0 and No.11-P-92045/0 from the U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services. However, the contents herein do not necessarily represent the policy of the U.S. Department of Health and Human Services, and you should not infer endorsement by the Federal government. The statements contained in this report are solely those of the authors and do not necessarily reflect the views or policies of the Centers for Medicare & Medicaid Services. The contractor assumes responsibility for the accuracy and completeness of the contained information.

Suggested Reference

Stamm, B.H., Kirkwood, A. D., Larsen, D., Piland, N.F., Spearman, R.C., Davis, K.S., Wolfley, D., Tivis, L., Tivis, R.L., Parker, D. (2006). Final Report: Idaho Systems Change Project. , Pocatello, ID: Idaho State University.

Key Contacts by Sections of the Study

Needs & Resources Assessment

Russell C Spearman, Med and B Hudnall Stamm, PhD

Community Development

Ann D Kirkwood, MA and B Hudnall Stamm, PhD

Anti-Stigma Campaign

Ann D Kirkwood, MA and Neill F Piland, DrPH

Effectiveness Study

B Hudnall Stamm, PhD, Debra Larsen, PhD, Kelly S Davis, MS

Economic & Financial Reports

Neill F Piland, DrPH (Economic), Daniel Wolfley, BAA, CPA and B. Hudnall Stamm, PhD (Financial)

Acknowledgements

Many people and organizations contributed to this project. The research team would particularly like to recognize following students, employees, and colleagues: Kelly Buckland, Leigh Cellucci, PhD, Heather K Conley, PhD, Cindy Dimmer, BA, Cameron Gilliland, Todd Hong, BBA, Amy C Hudnall, MA, Vidya Nandikolla, PhD, Stacy Specht, MPA, Chandra Story, MHS, Marilyn Sword, Ian Towend, and Rachel Wolf, MS.

TABLE OF CONTENTS

57

Table of Contents Page

ASSESSMENT

58

SECTION 1: EXECUTIVE SUMMARY

Idaho is the 14th largest U.S. state but contains the 12th smallest population with an average population density of 15 people per square mile, five times less than the national average. Idaho's population is concentrated in three geographical areas: northern Idaho (Coeur d'Alene area), eastern Idaho (Pocatello Idaho Falls area), and southern Idaho (Twin Falls, Boise, and neighboring cities). Thirty-six percent of the state's residents live in rural areas on 88% of the state's land. Thirty-five of the 44 total counties have fewer than 25,000 people and 92% of the towns have populations less than 10,000 (Stamm, 2003). An IRH geographic information systems (GIS) study found that more than 50% of the non-metropolitan Idahoans live at least 66 miles (straight-line distance) from the nearest tertiary healthcare facilities, while 25% live at least 95 miles, and 10% live 106 miles away from these facilities. The actual distance people travel to access care is even higher, as roads are seldom straight lines and other factors such as slope, type of road, and weather conditions increase travel complexities.

The Real Choices Systems Change Project (Real Choices) studies the effectiveness of various strategies in assisting people with all types of disabilities, including mental illnesses, and age-related disabilities to live full, productive lives within their communities. The project is funded by the Center for Medicare and Medicaid Services (CMS) of the United States Department of Health and Human Services (DHHS; #18-p-91537/0 and #11-p-92045/0). It is a collaborative effort between the state of Idaho and the Idaho State University Institute of Rural Health (ISU and IRH respectively). There are five key components to the project: (1) a statewide needs and resources assessment, (2) an anti-stigma media campaign, (3) an economic analysis, (4) a community development (CD) project, and (5) an effectiveness study.

The study includes extensive community participation. Along with the Idaho Department of Health and Welfare (IDHW), Idaho's Community Integration Committee (CIC) served as a monitoring board for the project. The CIC includes citizen/consumers and public and private agencies across all life areas (e.g., housing, transportation, healthcare, employment, etc.). Agency- and citizen/consumer-working groups assist with each of the project components.

Phase I (2001–2005) began with a statewide, mailed needs and resources assessment that used stratified random and snowball sampling methods. This led to a draft state plan; the basis for the Effectiveness Study. In 2003, Real Choices launched a statewide Anti-Stigma Campaign with assistance from the Idaho Department of Transportation, the Idaho State Broadcaster's Association, and others. A completed pre- and post-test, statewide random-sample phone survey will measure the effectiveness of the anti-stigma campaign. Also in 2003, a competitive request for proposals culminated in the selection of Jason and Associates and the Idaho Falls area (Bonneville, Bingham, and Jefferson Counties) to serve as a model community for the Community Development Project and Effectiveness Study.

Phase II (2003–2006) activities focus on (1) continuing the Anti-Stigma Campaign, designed to reduce stigma and facilitate community integration; (2) continuing the economic analysis of the current Medicaid system to identify ways to reapportion and maximize funding; (3) expanding the Community Development Project efforts to examine the political and fiscal feasibility of increasing resources for living within a community development perspective and to create a more hospitable community for people who wish to live in it; and (4) expanding the Effectiveness Study to test what best assists people of all ages with any type of disability or long-term illness in reaching their community integration goals.

Key Findings by Study Section

Needs & Resources Assessment

Most Disabilities Are Acquired After Birth. The statewide Needs and Resource Assessment showed that most of the reported disabilities were acquired after birth (72%). Half were acquired during adulthood, with 11% of these occurring after age 65.

Poverty Is Common. Socioeconomic status is negatively affected by the disability. More than half of the respondents (54.5%) reported total household income of less than $25,000 per year. The most commonly reported total household income was $15,000-24,000 (20%). Just over one third of respondents reported total household income of less than $15,000 per year (34.5%).

Autonomy Exists for Living Independently. 89% reported they are happy with the current residence. Of the 484 respondents, 380 (77%) lived in a home or apartment. Of these, only 20% owned their own home while 80% lived in rental housing. The remaining people reported living in a nursing home (3.6%), group setting (2%), homeless (<1%) or rehabilitation facility (<1%), home of a care provider (7%), or other (7%).

Many Experienced Discrimination. Nearly half of the participants (48%, n=233 reported experiencing discrimination in at least one area as a result of their disability and this accounts for a total of 410 reports across multiple life areas. Twenty-three percent (23%) experienced discrimination in medical care, 12% reported discrimination by their healthcare provider. Twenty three percent (23%) also reported discrimination in employment. Among these respondents nearly all of who lived in the community, only 7% reported discrimination in either housing or transportation.

Disability Has Caused Additional Health Problems. Between 159 and 209 (33 to 43%) respondents believed that their disability caused a life status change in their marriage or family, employment, living situation, medical health, psychological health, or social status. In addition, 53% of respondents believed their disability caused additional health problems, 26% believed it caused additional mental health problems, and 12% believed it caused additional oral health problems.

Quality of Life Is Better Before the Disability. Data describing the quality of life of the person with the disability prior to the disability and after showed, on average, a dramatic reversal with the largest group reporting above average or excellent quality of life prior to the disability. The largest group also reported a poor or below average quality of life after the onset of the disability. A similar pattern was observed among caregivers.

Community Development

Community Development & Public Participation Are Vastly Different. One of the common distresses of people with disabilities and those who provide their services and supports is that much talk about change occurs, but nothing changes. Certainly public participation and neutral facilitation are key aspects to system change because they permit expression of the voice of volunteers. However, the actual work of making those community changes is accomplished through CD, not public participation or facilitation. We believe that this piece of knowledge is so important that it alone can move communities forward merely from their good-faith efforts to include people with disabilities in their processes. Processes yielding no change despite people's clear desire can be thwarted without a commitment to, and understanding of, the principles and practices of CD.

Good CD Requires CD Expertise. To be successful at CD requires the expertise of a community resource developer specifically trained in this field. The complex mix of required skills is essential, including an understanding of economics, business, public participation, and urban/rural planning.

Neutral Facilitation Is Important but Insufficient for CD. While needed in a CD project like public participation, neutral facilitation alone is insufficient to achieve CD goals.

Build from Community Assets, Not Deficits. Although it is important to identify a community's needs and gaps, bringing about community change does not emanate from the deficits. The most effective approach is to look at a community's assets and see what can be done to improve on them. Identification of deficits can be motivating to identify the need to change; dwelling on deficits leads to despondence among those investing their energy in bringing about community change.

Anti-Stigma Campaign

Participants Reported a High Familiarity with Disabilities. Participants demonstrated a high level (95%) of familiarity with disabilities. This familiarity with some type of disability was observed in both the pre- or post-campaign randomized survey result.

Participants Reported Low Perceived Social Distance. Social distance was measured by three items relating to participant's perceived social distance to people with disabilities. Many respondents (n=357, 31%) reported low perceived social distance (comfortable or very comfortable around people with disabilities). Only 8% (n=88) indicated high levels of social distance (response in the uncomfortable to very uncomfortable range).

Participants Reported High Perceived Comfort in Their Communities. Respondents were comfortable or very comfortable (a) living, working, or going to school in a community with people with disabilities, (n=370; 43%); (b) living next door to someone with a disability (n=520; 61%); and (c) living with someone with a disability (n=344; 41%).

Participants Reported Low Perceived Discrimination/Fear in Their Communities. Many respondents perceived no discrimination (n=208; 18%) or fear (n=318; 28%) in their community toward persons with disabilities, with only a small percentage reporting a lot of discrimination (n=41; 4%) and fear (n=55; 5%).

Effectiveness Study

Integration Improves Quality of Life. Community integration is especially potent in decreasing the negative impact of disability on emotional functioning. Individuals reported that (even in the presence of physical functioning, mental health or cognitive limitations) the daily emotional impact of disability was lower with integration. This was accomplished with medical and life status domains remaining stable rather than deteriorating over time, regardless of disability category.

Most People Had More than One Disability. Seventy-five percent of participants reported a secondary disability in a different category of disability. Most typically this means that an individual with a primary physical disability is also experiencing mental illness (40%) or an individual with primary mental illness also has a physical disability (35%). This does not include multiple diagnoses (e.g., multiple medical difficulties) within one category.

Disabilities Affect Members of the Family Support System. The primary caregivers and family members of individuals with disabilities report personal disability rates 7.5–8 times that of the general population (U.S. Census, 2000). Integration is impacted by threats to the functional impairment of individuals within this critical support system.

Trauma Is a Common Co-Traveler with Disability. Individuals with disabilities reported 3-fold the exposure rate of the general public to potentially traumatic events and ongoing traumatic stress symptoms. We propose that the most successful integration strategies will support traumatic stress treatment and reduce risk for further trauma exposure due to the long-term implications of traumatic stress on mental and physical health.

Adult Males with Physical Disabilities Are at Risk for Depression. Adult males of employment age reported significantly higher levels of depression than all other groups. Intervention targeting disability adjustment in the face of gender role expectations and depression treatment may be critical to this group's integration and successful long-term outcomes.

Economic Analysis of the Effectiveness Study

Home & Community-Based Services (HCBS) Are Cost-Effective Alternatives to Institutional Care. There appears to be substantial opportunity for the provision of cost-effective long-term care services through home and community-based programs that meet the goals of both cost containment and client self-determination for Idaho Medicaid and Idaho's population affected by disability.

HCBS Have Evolved in Idaho Over Time. There was substantial activity and progress on the part of Idaho's disabled populations to develop alternatives to institutional long-term care well before the Olmsted decision (Olmsted v. LC, 1999). The decision did accelerate changes in the long-term care system and provided greater empowerment for people with disabilities and their advocates.

HCBS Have Helped Moderate the Cost of Institutional Care. Skilled nursing facility costs moderated in the last few years largely due to expansion of the HCBS-based waiver programs. This indicates that opportunity for further substitution of home and community services for institutional long-term care is increasingly attractive. It also offers the opportunity of either expanding the range of services offered in the community and /or the number of eligible recipients within the constraints of current budgets.

Idaho's HCBS-Waiver Program Has Grown Significantly & Is an Increasingly Important Component of Medicaid's Programs. From 1997 through 2002 the HCBS waiver program expenditures grew substantially as a proportion of total Medicaid and Medicaid long-term care expenditures: 10% of long-term care and 4% of total Medicaid in 1997 to 27.6% of long-term care and 9.5% of total Medicaid in 2002. This is an extremely significant trend that has continued through 2005.

More Participants Receive HCBS-Waivers (2003) than Institutional Services & Per Capita Costs Are Lower. However, per capita costs for recipients of long-term care services were $15,785 for HCBS and $47,554 for institutional care. The level of care required for most of the institutional care recipients may demand higher costs. However, based upon the historical expansion of these programs, it is very likely that a considerable proportion of Medicaid recipients of long-term care services can benefit from HCBS at a substantially lower cost than is now being realized.

Financial Analysis of the Effectiveness Study

Study Per Capita Costs for Community Integration Lower then Institutional Care. The financial analysis of the Real Choices Effectiveness Study generally supports the findings of the economic analysis suggesting that HCBS can be provided less expensively than institutional care for comparable populations of people with disabilities. The data support the hypothesis that expanding alternative services can offer cost-effective alternatives to institutionalization.

Small Incremental Expenditures May Lead to Big Dividends. Relatively small incremental expenditures may increase quality of life and functional status for both recipients and their families. Comparing baseline to exit scores on functional assessment measures, significant improvements in mental health and financial status were observed. Participants were able to maintain a life in the community; none of the participants needed to utilize institutional care during the time they were enrolled in the study.

The Family Is the Cost-Effective Unit. Without sustaining the social support system of the person with a disability, independence may not be attained and maintained. An individual with a disability and his or her defining family must be considered as a programmatic unit when dealing with issues of disability and the accompanying financial, health, social, and functional challenges. In the absence of family support, individual recipients have great difficulty in generating the resources and accessing the systems necessary to achieve and maintain independence.

Utilizing Current Systems Require Substantial Time Investments by Both the Person with a Disability & Those Assisting Them. Assessment, design, and implementation of Community Integration plans take substantial time. There are generally two types of time expenditures: time spent designing and implementing a CI plan and time accessing services and supports for which a person is eligible within their third-party payment system, Considerable staff and administrative resources were devoted to accessing each person’s eligible services. This cumbersome access problem characterizes a system undergoing rapid change and emphasis on greater availability of HCBS. Thus, expediting the system conversion from institutional care toward HCBS may be cost-effective.

Section References

New Freedom Commission on Mental Health. (2003). *Achieving the Promise: Transforming Mental Health Care in America. Final Report.* Washington, DC: GPO (DHHS Publication No. SMA-03-3832). Retrieved September 20, 2005 from http://www.mentalhealthcommission.gov/reports/reports.htm

Stamm, B.H. (Ed.). (2003). *Behavioral Healthcare in Rural and Frontier Areas: An Interdisciplinary Handbook*. Washington, DC: American Psychological Association Press.

U.S. Census. (2000). U.S. Census. Retrieved July 28, 2006, from http://www.census.gov/popest/states/asrh/tables/SC-EST2003-03/SC-EST2003-03-16.pdf

Public Draft of Idaho Real Choices System Change Project Report, August 10–August 31, 2006

Between August 1 and August 30, 2006, draft copies of the Idaho Real Choices Systems Change Project Report was made available to all study participants; members of the committees, businesses, associations, and state agencies listed in Appendix F; interested Federal parties; as well as the general public. We requested and received feedback on the report as a means of refining the final document and as a way of continuing our commitment to community empowerment. What is published here represents a compilation of our data and the response of qualitative data made available to us by so many people invested in the Real Choices Project. Our intent is to provide a fair and clear representation of the outcome of this study.

SECTION 2: AUTHOR AFFILIATIONS IN ALPHABETICAL ORDER

Kelly S Davis, MA
Graduate Research Assistant
Institute of Rural Health
Idaho State University
Pocatello, ID

Ann D Kirkwood, MA
Senior Research Associate
Institute of Rural Health
Idaho State University
Boise, ID

Dr Debra Larsen, PhD
Research Assistant Professor
Institute of Rural Health
Idaho State University
Pocatello, ID

Donna Parker, AA
Administrative Assistant
Institute of Rural Health
Idaho State University
Boise, ID

Dr Neill F Piland, DrPH
Research Professor
Institute of Rural Health
Idaho State University
Pocatello, ID

Russell C Spearman, MEd
Senior Research Associate
Institute of Rural Health
Idaho State University
Boise, ID

Dr B Hudnall Stamm, PhD
Research Professor and Director
Institute of Rural Health
Idaho State University
Pocatello, ID

Dr Laura Tivis, PhD
Research Associate Professor and
ISU Institute of Rural Health Boise
Center Coordinator
Institute of Rural Health
Idaho State University
Boise, ID

Ricky L Tivis, MPH
Biostatistician
Institute of Rural Health
Idaho State University
Boise, ID

Daniel Wolfley, BA, CPA
Research Associate
Institute of Rural Health
Idaho State University
Pocatello, ID

SECTION 3: AUTHOR BIOGRAPHIES IN ALPHABETICAL ORDER

Kelly S Davis, MS, is a Graduate Research Assistant at the ISU-IRH, prior to this position she worked as an Undergraduate Research Assistant at the IRH. Davis is a clinical psychology doctoral student and received both her Master's and Bachelor's degrees in Psychology from ISU. In 2003 she was awarded the ISU Art's and Sciences Student of the Year award. She has also been awarded the Best Undergraduate Poster in 2001 and Best Graduate Poster in 2006 at the Idaho State Psychological Association Annual Conference. Davis is currently serving as the secretary for the ISU Psychology Graduate Student Association and is the Student Sector Representative for the Idaho Psychological Association. She also volunteers for Big Brother's, Big Sister's of America, Pocatello Chapter and has a 9-year-old little sister through this program. Davis has presented research at local, national, and international conferences and continues to pursue her academic and career goals. Davis' efforts focus on secondary trauma for healthcare providers, children's traumatic stress interventions, and the comorbidity of substance abuse and post traumatic stress syndrome (PTSD), particularly with incarcerated women. Davis will be completing her dissertation research on comorbidity in incarcerated women and hopes to graduate with her PhD in clinical psychology in 2008 following completion of her doctoral internship

Ann D Kirkwood, MA, ISU-IRH, specializes in social marketing and has directed the Better Todays. Better Tomorrows. (B2T2) school-based children's mental health gatekeeper training program since its inception in 2000. B2T2 is designed to reduce stigma about mental health problems in children and youth and encourage timely and appropriate treatment by adults on behalf of children in their care. Educational programs have been customized for parents, educators, Spanish-speakers, and law enforcement. The effort falls under an anti-stigma campaign Ms. Kirkwood developed while directing public relations and social marketing campaigns for the IDHW from 1991–2000, winning media awards from the National Public Health Information Coalition. She managed an anti-stigma multi-media campaign in 1997–2000 that won a prestigious *International George Peabody* award for excellence in broadcasting, an excellence in public information award from the National Alliance on Mental Illness, an excellence in public broadcasting award from the National Educational Television Association, and a Telly Award. As a reporter and editor for 18 years, Ms. Kirkwood also won two national awards for editorial writing from the National Newspaper Association and numerous regional and state awards for reporting and editing. She designed a collaborative model for social marketing planning that involves people with disabilities creating their own campaigns that reflect the unique, deleterious consequences of stigma on their lives, and does so with measurable impacts on the attitudes/behaviors of target adopters. Ms. Kirkwood has used the model successfully with several social marketing campaigns relating to mental illness and community integration for people with disabilities. She also has been retained by IDHW to prepare a comprehensive training program for rural and frontier community members involved in community integration on behalf of people with disabilities. Ms. Kirkwood serves on the Idaho State Board of Psychologist Examiners and is active in the National Alliance for Mental Illness. She completed her undergraduate work at the University of Washington and a master's degree in communications from Boise State University

Debra Larsen, PhD, is a Research Assistant Professor for ISU-IRH. She was the 2004 recipient of the American Telemedicine Association's grand prize for Poster of Scientific Merit and a recipient of a faculty loan repayment fellowship from the HRSA Bureau of Health Professions. Dr. Larsen has significant clinical experience implementing interventions with children/adolescents and their families who experienced exposure to violence or trauma through her work with a number Idaho's family crisis centers. Additionally, her work at the Munroe-Meyer Institute at the University of Nebraska Medical Center focused on addressing barriers and providing pediatric mental health treatment in rural/frontier areas. Dr. Larsen is a member of the Idaho Psychological Association and is their state Academic Representative. She is a member of several national and international associations, including the American Psychological Association, the Association for the Advancement of Behavior Therapy, the American Telemedicine Association, the International Society of Traumatic Stress Studies, and the National Association for Rural Mental Health. Dr. Larsen has presented research findings regarding family interaction patterns; parental support; child/adolescent mental health; rural service provision; and secondary trauma at regional, national, and international conventions. Dr. Larsen's publications have focused on social support within family relationships, rural adolescent aggression, rural applications of telehealth, rural healthcare service issues, and secondary trauma.

Donna Parker, AA, has her Associate's Degree in Secretarial/Legal Studies from Eastern Idaho Technical (College). She is an Administrative Assistant for ISU-IRH at the Boise Center. Paker works with the IRH Boise grant researchers and the IRH Boise Center Coordinator. She has assisted with grant document preparation and submission for the Traumatic Brain Injury Implementation grant; Alcohol, Cognition and Estrogen Replacement Therapy in Post-Menopausal Women grant; B2T2 grant; and Real Choices. Parker also worked with the Idaho Commission on Nursing and Nursing Education through in-kind donations provided by ISU, Department of Nursing, on three grant projects (Robert Wood Johnson, Helene Fuld Grant and the Murdock Foundation) to facilitate nursing and nursing education in the state of Idaho.

Neill F. Piland, Dr PH, is a Research Professor at ISU-IRH. Previous to that he was Director of the Medical Group Management Association (MGMA) Center for Research and Director of the New Mexico's Lovelace Institute for Health and Population Research. A health economist and health services researcher, he received his doctorate in Health Services Administration from UCLA and also holds master's degrees in public health and in economics. He has been a principal investigator for more than thirty major research and demonstration projects including an evaluation of the quality of care in Arizona's Medicaid managed care experiment, the New Mexico project for the Community Intervention Trial for Smoking Cessation site, and a national study of Physician Profiling. He has authored or coauthored over ninety articles, four books, and numerous book chapters on healthcare delivery, health promotion, and healthcare financing. He is currently directing economic analysis for IRH's Real Choices, the Telehealth, and the National Center for Child Traumatic Stress programs. He is also IRH's Principal Investigator for the Idaho Bioterrorism Awareness and Preparedness Program (IBAPP).

Russell C Spearman, Med, is the Project Director for Idaho's Traumatic Brain Injury Partnership Implementation grant from the Health Resources Services Administration (HRSA), Maternal and Children's Health Bureau. Since August 2000, Spearman has been employed by ISU-IRH. Prior to this, he was responsible for developing and implementing all aspects related to Idaho's 1915 C Medicaid HCBS Waiver for adults with a traumatic brain injury. He is the former Executive Director for Idaho's Governor's Council on Developmental Disabilities and the lead author of "The Use of Medicaid Waivers and Their Impact on Services." During this time Spearman was instrumental in developing and successfully transitioning Idaho's nationally recognized Home of Your Own Initiative that today has assisted over 75 people with disabilities realize their dream of home ownership, a program that garnered him national recognition in 1997 for his vision and leadership. He is married with two children, one who experienced a traumatic brain injury in 1993. In part, this led to his 25 year work in which he assisted in the passage of several pieces of legislation on behalf of Idahoans with disabilities. He received an undergraduate degree from Manhattan College and his master's degree in school administration from the College of Idaho (Albertson's College). In terms of social service, Spearman was recognized by the National Association of Social Workers, Idaho Chapter in 2002 as the public citizen of the year for his work with people with disabilities. He serves on public policy committees for the Brain Injury Association of America (BIA-A) and the National Association of State Head Injury Administrators (NASHIA). For the past twenty years he and his wife, have been adult family home providers to a gentleman with a developmental disability who is competitively employed.

B Hudnall Stamm, PhD, educated in psychology and statistics at Appalachian State University (BS, MA) and University of Wyoming (PhD), is a Research Professor; Director of the National Child Traumatic Stress Center for Rural, Frontier, and Tribal Health; and Director of the ISU-IRH. She has held appointments at Dartmouth Medical School and the University of Alaska. She is the recipient of awards from the International Society for Traumatic Stress, the American Telemedicine Association, the National Rural Health Association, and from the American Psychological Association where she was recognized as being "one of the outstanding psychologists of this generation." Her work focuses on rural underserved peoples in health policy, cultural trauma, and secondary traumatic stress among healthcare workers. She is an Associate Animal Behavior Consultant with the International Association of Animal Behavior Consultants and on the Delta Society Service Animal Trainer Registry. With over 100 professional publications, her books include *Secondary Traumatic Stress* (1995, 1999, Sidran Press, English, German, & Japanese editions), *Measurement of Stress, Trauma and Adaptation* (1996, Sidran Press), *Cultural Issues and the Treatment of Trauma and Loss* (with Nader and Dubrow, 1999, Brunner/Mazel) *Rural Behavioral Health Care* (APA Books, 2003) and *The Professional Quality of Life Test Manual* (Sidran, 2005). Her work is used in over 30 countries and diverse fields including healthcare, disasters, media, and the military. See www.isu.edu/~bhstamm and www.isu.edu/irh.

Laura Tivis, PhD, is currently Research Associate Professor ISU-IRH, Boise, and is the Principal Investigator on a R01 grant, now in its eighth year, from the National Institutes of Alcohol Abuse and Alcoholism (NIAAA) entitled Alcohol, ERT and Cognition in Postmenopausal Women. Dr. Tivis earned a BA degree in psychology from Boise State University. She left Idaho to pursue graduate study, subsequently earning a M.S. in clinical psychology from Eastern Washington University and a Ph.D. in biological psychology from the University of Oklahoma (OU) Health Sciences Center. Her major area of study at OU was in chronic alcohol effects on neuropsychological functioning. After receiving her doctorate, she pursued postdoctoral training at the Oklahoma Medical Research Foundation andthe Oklahoma Center for Alcohol and Drug-Related Studies where she studied alcohol/estrogen interactions and electrophysiology in moderate drinking and heavy drinking populations, respectively. She later joined the faculty at the Oklahoma Center for Alcohol and Drug-Related Studies and became the Associate Director of the Center and the Assistant Director of the Biological Psychology Ph.D. program. Dr. Tivis has taught medical students, graduate students, and clinical psychologists about the effects of alcohol on elderly populations. Since 1997, Dr. Tivis has been funded to study cognitive effects associated with moderate drinking among postmenopausal women. She returned to Idaho in 2004 bringing her research interests in substance abuse and elderly populations to her native state.

Ricky L Tivis, MPH, from the University of Oklahoma Health Sciences Center, having completed a Masters in Public Health emphasizing Biostatistics and Epidemiology. He joined ISU-IRH, Boise in 2004. He came to Idaho from the OU Health Sciences Center where he held appointments as Adjunct Assistant Professor in the College of Medicine with Department of Psychiatry and Behavioral Sciences and simultaneous appointments in the Collage of Public Health and the Department of Biostatistics and Epidemiology. He serves as an IRH statistical consultant and analyst. He is Co-Investigator on the NIAA Alcohol, ERT and Cognition in Postmenopausal Women grant. Over the past 16 years, his primary research focus has been in the area of substance abuse. He continues collaborative work at ISU and as a private consultant to researchers at universities in Kentucky, Oklahoma, Colorado, Minnesota, and Connecticut.

Daniel Wolfley, BAA, CPA, Dan Wolfley is the Project Coordinator for Idaho's Real Choices since November 2004. He was a co-author of two posters presented to CMS from the Real Choices Effectiveness Study data. He worked closely with the CD portion of the project, managed the project databases and helped with analysis of the data. Dan received his BBA degree from ISU and is licensed as a CPA. Dan worked in grant accounting at ISU for 11 years, eight of which he was the director.

SECTION 4: INTRODUCTION

Idaho covers 82,750 square miles of terrain from mountains to plains with climates ranging from desert to alpine. The population density is 15 people per square mile, five times less than the national average. Approximately 1/3 of Idahoans live in the Boise area, yet 90%of Idaho's towns have populations less than 10,000. Idaho's per capita family income ($18,170) was 43rd in 1997. There are 43 designated health professions shortage areas (HPSA); 93% of the state. In 75% of the counties, people must drive 50+ miles to a tertiary care center.

Idaho Department of Health and Welfare (IDHW) is an umbrella agency reporting directly to the Governor and includes the Divisions of Health, Information and Technology Services, Human Resources, Family and Community Services, Medicaid, Welfare, and Management Services. The Director oversees all department operations. They are advised by a seven-member Board of Health and Welfare appointed by the Governor.

IDHW has seven divisions representing over 30 health, welfare, and human service programs. Each division provides or supports services through a privatized system or partnerships with other agencies and groups to help people in communities. IDHW has seven regional offices and 42 field offices statewide that provide services. The department values the life areas approach advocated in the New Freedom Initiative and fosters relationships with other Idaho departments including Vocational Rehabilitation, Labor, Education, Transportation, Idaho Commission on Aging, Idaho Housing Finance Association, Juvenile Corrections, and advocacy groups. Consultation and collaboration with persons with disabilities, providers, advocates, families/guardians, and the public are integral to IDHW's management strategies.

Idaho has a comprehensive state Medicaid Plan. Under this plan, people with disabilities are entitled to an array of mandatory and optional services. In 1995, the Department initiated the Community Supports project designed to provide Medicaid-eligible people with developmental disabilities and their families/guardians with increased choice of community-based services and supports. Similar programs for other types of disabilities and long-term illnesses also exist.

Facilities & Programs

Departmental services are delivered statewide through seven Health and Welfare service regions. Each service region has a Regional Director who reports to the Department Director. All Community Mental Health Centers, Adult and Child Development Centers, and Family and Children's Services Centers in Idaho are state-operated. With the exception of Substance Abuse services, all services are provided through the regional system with each region comprising a specific catchments area. Substance abuse services are administered by IDHW directly, which contracts for program management and prevention and treatment services. The Department, in partnership with local community representatives, sets priorities and standards, monitors contracts, and provides leadership and technical assistance. IDHW operates two psychiatric hospitals, State Hospital North and State Hospital South, and the Idaho State School and Hospital for persons with severe developmental disabilities.

IDHW operates an intermediate care facility for adults and children with developmental disabilities, Idaho State School and Hospital (ISSH), in Nampa, Idaho, serving approximately 112 individuals. ISSH serves primarily two types of clients—those with severe behavioral difficulties who have problems with safety in respect to self or others—and those transitioning to a higher level of care into a community setting. IDHW also operates two hospitals for adults and children with mental illnesses, State Hospital North (SHN) in Orofino, Idaho, and State Hospital South (SHS) in Blackfoot, Idaho. SHN has a total of 60 beds with 20 devoted to severe mental illness, 20 to dual diagnosis (substance abuse and mental illness) patients, and 20 to substance abuse alone. It had a daily occupancy rate in fiscal year (FY) 2000 of 77%, with a re-admission rate of 39% for psychiatric treatment. SHS has a total of 90 adult beds, 16 adolescent (ages 12–17 years old) beds and another 30 beds for skilled nursing (elderly) services. The average daily occupancy rate for SHS was 83 % in FY2000 with a re-admission rate of 40%. Re-admission rates reflect Idaho's status as a severely underserved state in all types of healthcare (physical, mental, and oral) combined with poor resources in housing and problems with access to medications/non-compliance.

All facilities (ISSH, SHN, SHS) are designed to offer short- and intermediate-term treatment until a person is stabilized and ready to move to the community. In-home placement is encouraged for children through the provision of outpatient therapeutic services and support services for the child and family. From the admission date, staff coordinate with regional developmental disabilities, mental health, and/or Medicaid staff to have a discharge plan that provides maximum flexibility and choice in housing, transportation, employment, and access to appropriate medications and medical services. About 13% of patients admitted to the state hospitals remain in excess of 60 days past their point of stability because of a lack of community options.

The Developmental Disabilities (DD) program has regional offices. Supported employment is offered to 1,050 adults, with 157 awaiting initial employment as of March 2001. Families receiving financial supports total 834, with $304,323 obligated in the first three quarters of FY2001. A total of 1,274 children were enrolled in the Infant/Toddler Program as of December 2000; 88% of services were provided in natural environments, and 81% had steps to independence in their service plans. A DD waiver is described more fully below.

Mental health services offered to adults in the community include targeted case management, crisis interventions, and Assertive Community Treatment (ACT). Case management for people with serious mental illnesses includes service linkages, client advocacy, coordination of services, and symptom management. 24/7 telephone crisis intervention is used to mobilize community resources and providers to stabilize crises and avoid institutional placement. In the late 1990s, an effort to write a mental health Medicaid waiver was mounted, but it was not completed for a variety of administrative and political reasons.

Challenges for mental health programs include funding, quality assurance, and a high suicide rate. In 1997, the latest year for which figures are available, Idaho ranked as the 47th lowest state in per capita spending on public mental health services. ACT Teams are endorsed by IDHW and are a preferred practice, but they are not available in rural areas. Similarly, Crisis Response Teams are available sporadically. The Centers for Disease Control ranks Idaho seventh in the nation for per capita hospitalization and rate of disability due to traumatic brain injury. Idaho's suicide rate is the 5th in the nation overall and the 3rd for young people ages 15-25. An anti-stigma education campaign to change negative perceptions of mental health and about people with disabilities was launched in 1999 using an educational video that received an International Peabody Award for broadcasting as well as an excellence in television award from the National Alliance for the Mentally Ill. The television public service announcement in the campaign won a Telly Award. This campaign has been continued and expanded to all disabilities and long-term illnesses under the current Idaho Real Choices System Change Grant.

In an effort to expand available community-based services while being mindful of limits on the number of IDHW personnel, privatization was actively pursued. One example of the effort to place public resources at a community-level is in the form of children's mental health services. While the rate of juvenile hospitalization at SHS remained stable from FY1998 to 2000, contracts for community activities increased from 3,050 in FY1998 to 8,388 in FY2000. Also, under the 1995 Community Supports Program for Adults with Developmental Disabilities, IDHW staffing levels were augmented by (a) targeted service coordinators who help obtain services an individual identifies (90 + private providers statewide); (b) private residential habilitation providers (1,209 statewide), and (c) 62 private developmental disabilities agencies that assist a total of 3,005 people with developmental disabilities to learn life skills.

Medicaid is the primary source of funds for people with serious disabilities/long-term illnesses served by the state system. In FY2002, 146,956 Idahoans, which includes 105,091 children, received Medicaid-funded services. Medicaid funds services to people living in Intermediate Care Facilities for the Mentally Retarded (ICFsMR), nursing facilities, as well as community supports/services. Nursing facility costs reached about $120 million in FY2002, second only to costs for hospital care, which was $149 million. ICFsMR received about $34.6 million. Reimbursement under the DD, ISSH, Aged and Disabled, and traumatic brain injury (TBI) waivers totaled $77.8 million in FY2002. Services to support community placements totaled $115.1 million. Both the mental health and developmental disabilities programs are affected by FY2000 legislation that requires IDHW to limit the rate of growth in Medicaid. Planning is under way and the overall impact is unknown, although the goal is to assure that people with disabilities receive high-quality services of the amount and type from which they are most likely to benefit.

Home- & Community-Based Services (HCBS) 1915C Waivers

Idaho has three waivers: the Aged and Disabled (A&D), DD and ISSH, and TBI. Regional staff conduct biennial quality assurance reviews of a sample of participants and census of providers, except Certified Family Homes (CFHs). Under the A&D waiver, a census of CFHs is done annually; the DD/ISSH and TBI waivers undergo a biannual 30% sample review. A statewide review is conducted annually. Departmental rules (HW 623 and HW 16.03.09.118.02.a.ii) assure participant input regarding the assessment and plan development. Where appropriate, participants signed an Individual Service Plan and Informed Consent. Services must be provided in a coordinated, person-centered manner (16.03.09.118.02.a.ii).

The A&D waiver is the State's most widely implemented waiver, with an average of 3,647 enrollees. The number of participants has more than doubled since SFY (State Fiscal Year) 2000. State and Federal matching monies fund this waiver. The monthly average served under the A&D waiver are for SFY 2000, 1380 people; SFY 2001, 2597 people; and SFY 2002, 3647 people. The total yearly expenditures for the A&D waiver are: SFY 2000, $12.4 million dollars; SFY 2001, $29.4 million dollars; and SFY 2002, $46.3 million dollars.

The Developmentally Disabled/Idaho State School and Hospital Waivers served an average of 1,028 consumers monthly during SFY 2002, up 68% from 2000. The growth trend continues in SFY 2003 with a projected average of 1232 people. The DD waiver allows more flexibility and increased choices for enrollees, who traditionally would receive services in an intermediate care facility. State and federal matching monies fund this waiver. The monthly averages served under the DD waiver are: SFY 2000, 612 people; SFY 2001, 855; and SFY 2002, 1028. The total yearly expenditures for the DD waiver are: SFY 2000, $16.4 million;

SFY 2001, $21.2; and SFY 2002, $28.2 million. Under Idaho House Concurrent resolution 013 (2003), the Idaho Council on DD is directed to convene a Task Force to develop a new self-determination Medicaid model waiver that would support up to 200 adults with developmental disabilities to choose a different way of receiving services. The DD Council is pursuing a grant from CMS under the 2003 Independence Plus option of the Real Choices grant series. The ISSH waiver supported services to 57 individuals during the SFY 2002. These individuals would otherwise have been institutionalized at ISSH. State and Federal matching monies fund this waiver. The monthly averages served under the ISSH waiver are: SFY 2000, 41 people; SFY 2001, 53; and SFY 2002, 57, SFY2003 is projected at 60. The total yearly expenditures for the ISSH waiver are: SFY 2000, $1.6 million; SFY 2001, $2.2 million; and SFY 2002, $2.6 million.

The TBI waiver is for adults who suffer a TBI after they are 22-years old and would need to be institutionalized in the absence of this service. Nine people were enrolled in this program in SFY 2002. State and Federal matching monies fund this waiver. The TBI waiver monthly average is 1 person in SFY 2001, 5 in SFY 2002 and 9 in SFY 2003. The total yearly expenditures are: SFY 2000, $30,000; SFY 2001, $500,000; and SFY 2002, $730,000. With a DHHS, HRSA Maternal Child Health Bureau State Traumatic Brain Injury Program grant, IDHW and ISU-IRH are building a virtual program center to increase access and improve care for people with TBIs and their families.

The Idaho Community Integration Committee (CIC)

In September 2000, IDHW Director Karl Kurtz, appointed the Community Integration Committee (CIC) to assess the current service delivery system for consumers with disabilities. Special attention was given to determining issues, barriers, or gaps within the current system and providing recommendations to the Director. Following completion of an initial report in June 2001, the CIC was reorganized to better address cross-disability issues. The CIC shares a vision of a future where all Idahoans have the opportunity to live with dignity and respect and have meaningful choices as equal members of their communities. True community integration is full participation by people with disabilities in the same activities, in the same environments as their peers without disabilities.

The original committee was organized based on disability type. This focus has since shifted to cross-disability across life areas to mirror changes in the New Freedom Report Executive Summary (New Freedom Commission on Mental Health, 2003), to address shared goals and challenges. The reorganized committee is divided into sub-committees that address cross-disability issues of access to services, housing, transportation, education, and employment. This shift was further refined to incorporate aspects of the structure of the President's New Freedom Initiative. The CIC is comprised of consumers, family members, advocates, community professionals, and representatives from relevant associations and agencies including: the Council on Developmental Disabilities, Co-Ad, Vocational Rehabilitation, Housing and Finance, Commission on Aging, Mental Health Planning Council, Special Education, Transportation, AARP, the Idaho Department of Labor, and the IDHW.

CIC's major activities have focused on (a) understanding the current needs, gaps, and barriers of people with disabilities and (b) making recommendations as to what changes would benefit the continued community integration of people with disabilities in the State. This has been accomplished in two ways. First, the sub-committees have conducted their own research resulting in two Interim Reports to the Governor (2001 and 2002). Second, the CIC has provided research, information, and guidance to IRH to conduct research on behalf of the State under the Real Choices grant (#18-P-91537/0). The First Interim Report to the Governor (2001) provided the basis for Idaho's current grant, which runs October 2001 to September 2003. The Second Interim Report to the Governor (2003) is referenced below and forms the basis for this proposal for the continuation of Idaho Real Choices.

The goal of this project is to create enduring systems change in community long-term services and supports for people with disabilities, long-term illnesses, and aging. The plan for change is in two phases, first to understand and prepare the community, creating a plan for change, and second, to test the plan through an effectiveness study. There are four objectives, to increase or maintain access; availability and adequacy; value; and quality of services and supports.

The project uses five main parts to meet the study goals and objectives, all focused toward making the community a hospitable place for all its citizens, regardless of ability.

1. Statewide Assessment of Needs and Resources to develop a baseline and benchmarks of needs and resources for people of any age with disabilities and long-term illnesses in the state of Idaho.
2. Anti-Stigma Campaign designed to reduce stigma thereby paving the way for more successful community integration.
3. Community Development Project to examine the political and fiscal feasibility of addressing access to resources for living by approaching it as a community development problem, not a healthcare problem.
4. Effectiveness Study to determine the quality and value of the derived plan. The final product will be a plan for statewide implementation that has more integration of services, consumer and stakeholder input, and a monitoring system for continuous quality improvement.
5. Economic Analysis of the current Medicaid system to maximize appropriate funding strategies and leveraging of available funds.

Section Reference

New Freedom Commission on Mental Health. (2003). *Achieving the Promise: Transforming Mental Health Care in America. Final Report.* Washington, DC: GPO (DHHS Publication No. SMA-03-3832). Retrieved September 20, 2005 from http://www.mentalhealthcommission.gov/reports/reports.htm.

SECTION 5: STATEWIDE NEEDS & RESOURCES ASSESSMENT

The Needs and Resources Assessment was used to develop a baseline and benchmarks of needs and resources for people of any age with disabilities and long-term illnesses in the State of Idaho.

Methodology

A statewide needs and resources assessment was conducted with 485 Idahoans with disabilities or their family members and 98 agencies or organizations from multiple types of settings. Participants were selected through a stratified random sample across independent living, nursing homes/long-term care, developmental disabilities, or mental illness (adult and child). Surveys were mailed or, when there was a need for assistance such as in nursing homes, completed using a structured interview format.

In fall 2002 the measure used was a modification of a previously used needs and resources assessment. It was developed by researchers at IRH in collaboration with consumers and advocacy organizations as well as a working group from Idaho's CIC.

There are two versions, one for agencies, organizations, or individual providers and one for persons with disabilities, their family members, or significant others. The Agency Version asks for identifying information. The Individual/Family with Disability version requires no personally identifying information and can be answered by the person with disability or by another on their behalf.

Below, in Table 5-1, is shown the final theoretical review of the measure. The goal of the final review was to ensure a measure that was balanced by life area: (a) Self-Determination, (b) Employment, (c) Housing, (d) Health, (e) Information/Education, (f) Community Support, and (g) Transportation. All items selected for this final theoretical review had shown good item-to-scale predictability in psychometric analyses of the first version. Because the original measure was far too long to use for this particular study, items were selected for inclusion based on (a) advisory group guidance, (b) psychometric qualities, (c) ease of answering, (d) appropriateness for quantitative analysis, and (e) balance for the measure by life areas. Items were rated by their contribution to the life area as high, medium, or low contribution. The high items were tallied to endure a balance. Low items were kept only if their negative contribution was not expected to detrimentally affect another part of the measure. (Full copies of both the Individual/Family and Agency measures are included in Appendix B.)

Table 5-1: Theoretical Match of Selected Items to Be Included in the Individual/Family Version of the Needs & Resources Measure

		Life Area by Survey Item/Variable Information					
	Self-Determination	Employment	Housing	Health	Information & Education	Community Support	Transportation
Regarding Person with Disability							
County of Residence	m	h	h	h	m	h	h
Age	m	m	l	l	l	m	l
Age at First Onset	h	m	l	m	m	m	l
Age at Secondary Onset							
Sex	m	l	l	l	l	m	l
Type of Disability	h	h	h	m	h	h	h
Housing Status	h	m	h	l	0	m	m
Housing Status, Rent or Own	h	h	h	l	l	m	m
Live with Whom	h	l	h	m	m	m	m
Roommate Choice	h	0	h	l	l	m	l
Happy with Where Living	h	m	m	m	l	m	l
Regular Source of Medical Care	m	m	l	h	m	m	m
How Often See Family Dr.	h	m	l	h	h	m	m
How Many Miles to See Dr.	h	m	m	m	l	l	h
How Long Was Stay (# Days)	m	m	l	h	l	m	m
Want Telehealth	h	m	m	h	m	m	l
Education	m	m	l	l	m	l	l
Work Evaluation Status	m	m	l	m	m	m	l
Type of Work Evaluation	m	m	l	m	m	m	l
Employment Status Since Onset	m	h	l	l	l	m	l
If Not Working, Why Not Working?	m	h	l	m	m	m	m
Household Income	h	h	h	h	h	m	m
Source of Income	h	h	m	l	m	m	l
Transportation on Daily Basis	m	h	m	m	m	m	h
Disability Affected Life Areas	h	m	m	h	h	h	h
Quality of Life Before Disability	h	h	h	h	h	h	h
Quality of Life After Disability	h	h	h	h	h	h	h
Needs Help with Housing	m	m	m	m	m	h	m
Needs Help with Job Training	m	m	l	m	m	m	m
Needs Help with Employment	m	l	l	m	l	l	m
Needs Help with Personal Care	m	l	h	h	l	m	h
Needs Help with Chores	l	l	l	l	l	m	l
Needs Help with Transportation	m	h	m	l	l	m	l
Needs Help with Speech Therapy	l	l	l	l	l	l	l
Needs Help with Nursing	l	l	l	l	l	l	l
Needs Help with Recreation	l	l	l	m	m	m	m
Needs Help with Money Management	m	m	m	l	l	l	l
Needs Help with Community Skills Training	m	m	m	m	h	h	h
Needs Help with OT	l	l	m	m	l	m	m
Needs Help with Pain Mgt	m	m	m	h	m	m	h
Needs Help with PT	l	l	m	m	l	m	m
Needs Help with Mental Health Counseling	l	h	m	m	l	m	m
Needs Help with Nutrition	l	l	m	m	h	h	m

Needs Help with Post Sec. Education	m	m	m	m	h	h	m
Needs Help with Assistive Technology	m	m	m	m	h	h	m
Needs Help with Other							
Received Help with Housing (coded yes,no)	m	m	m	m	m	h	m
Received Help with Job Training	m	m	l	m	m	m	m
Received Help with Employment	m	l	l	m	l	l	m
Received Help with Personal Care	m	l	h	h	l	m	h
Received Help with Chores	l	l	l	l	l	m	l
Received Help with Transportation	m	h	m	l	l	m	l
Received Help with Speech Therapy	l	l	l	l	l	l	l
Received Help with Nursing	l	l	l	l	l	l	l
Received Help with Recreation	l	l	l	m	m	m	m
Received Help with Money Management	m	m	m	l	l	l	l
Received Help with Community Skills Training	m	m	m	m	h	h	h
Received Help with OT	l	l	m	m	l	m	m
Received Help with Pain Mgt	m	m	m	h	m	m	h
Received Help with PT	l	l	m	m	l	m	m
Received Help with Mental Health Counseling	l	l	m	m	l	m	m
Received Help with Nutrition	l	l	m	m	h	h	m
Received Help with Post Sec. Education	m	m	m	m	h	h	m
Received Help with Assistive Technology	m	m	m	m	h	h	m
Received Help with Other							
Satisfaction with Help Received—Housing	m	m	m	m	m	h	m
Satisfaction with Help Received—Job Training	m	m	l	m	m	m	m
Satisfaction with Help Received—Employment	m	l	l	m	l	l	m
Satisfaction with Help Received—Personal Care	m	l	h	h	l	m	h
Satisfaction with Help Received—Chores	l	l	l	l	l	m	l
Satisfaction with Help Received—Transportation	m	h	m	l	l	m	l
Satisfaction with Help Received—Speech Therapy	l	l	l	l	l	l	l
Satisfaction with Help Received—Nursing	l	l	l	l	l	l	l
Satisfaction with Help Received—Recreation	l	l	l	m	m	m	m
Satisfaction with Help Received—Money Management	m	m	m	l	l	l	l
Satisfaction with Help Received—Community Skills Training	m	m	m	m	h	h	h
Satisfaction with Help	l	l	m	m	l	m	m

Received—OT							
Satisfaction with Help Received—Pain Mgt	m	m	m	h	m	m	h
Satisfaction with Help Received—PT	l	l	m	m	l	m	m
Satisfaction with Help Received—Mental Health Counseling	l	l	m	m	l	m	m
Satisfaction with Help Received—Nutrition	l	l	m	m	h	h	m
Satisfaction with Help Received—Post Sec. Education	m	m	m	m	h	h	m
Satisfaction with Help Received—Assistive Technology	m	m	m	m	h	h	m
Satisfaction with Help Received—Other							
Family/Friends' Needs Assessment							
Caregiver Sex	m	l	l	l	l	m	l
Age	m	m	l	l	l	m	l
Education	m	m	l	l	m	l	l
Occupation	m	m	l	l	l	m	l
Income	m	h	h	h	h	m	m
Need Respite Care	m	m	m	m	l	m	l
Need Training in How to Care	m	m	l	m	m	l	l
QOL Before	h	h	h	h	h	m	h
QOL After	h	h	h	h	h	m	h
# of Hs	17	17	15	18	21	20	17

Procedures

The research was approved by the ISU Human Subjects Committee.

A census approach was adopted by saturating the available listings with mailed and internet-based surveys. Potential respondents were contacted through lists from Independent Living, Long-Term Care, Developmental Disabilities, and Mental Illness for adults and children.

To reach a significant portion of people in each major disability category, mailings were made to the universal contacts from lists supplied by membership, advocacy, professional association, state government, and health research and delivery organizations.

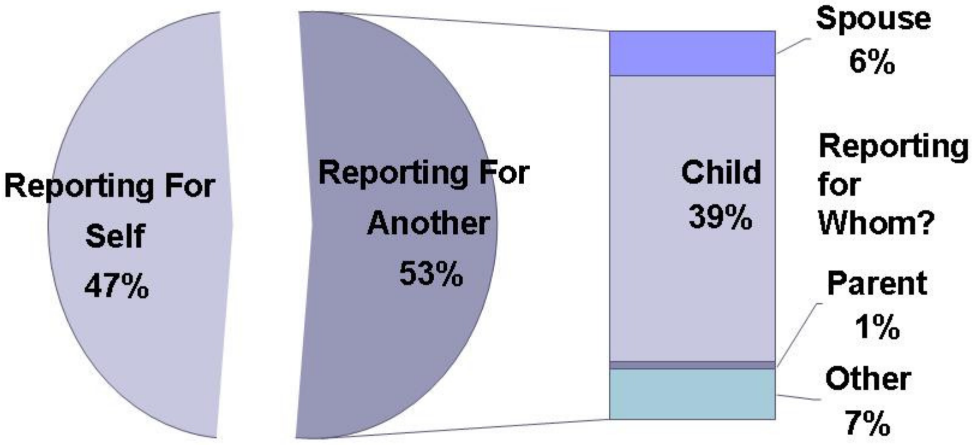
Participants were asked to complete the measure online, use the mailed paper copy, or call for assistance. Assistance included having someone read the measure over the phone; allow a respondent to complete the survey at one of several advocacy, research, or agency offices around the state; or have someone travel to the respondent's house.

Results

A variety of public and private agencies and organizations responded. On average, they reported their client services being reimbursed 25% by Medicaid, 8% by Medicare, 11% by private insurance, 16% by other sources (including contract services), and 40% unspecified. While there was no information about the unspecified percent, it is possible that this represents the percent of unreimbursed services.

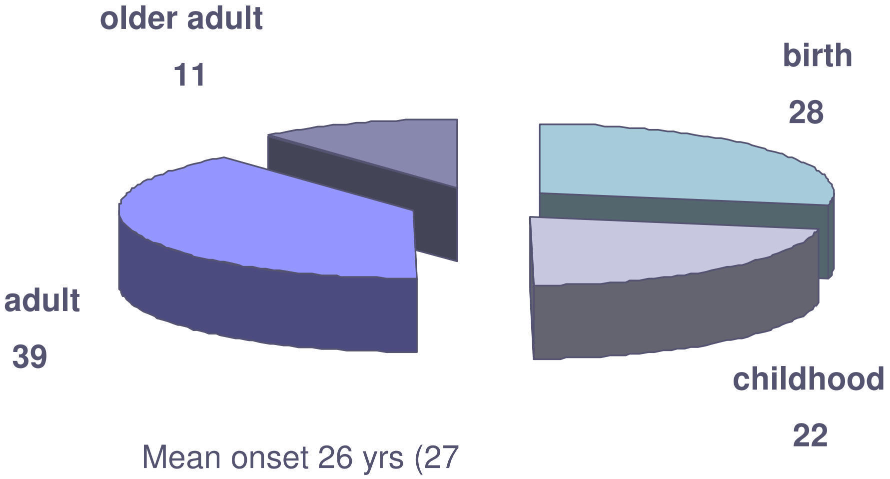
Regarding respondents to the disability measure, 47% responded for themselves and 53% responded for another. Among those responding for others, 39% responded for a child, 6% responded for a spouse, 1% for a parent, 7% for another. See Figure 5.1 below for more information.

Figure 5.1. Reporting Individual



Among the people with disabilities, the average respondent was 40 years old with a standard deviation of 27 years and an age range of 0 to 97. Twenty-eight percent of the represented people with disabilities had their initial onset at birth, 22% during childhood (1-18 years old), 39% had their initial onset as adults, and 11% as adults over age 65. The mean age of onset for the initial disability was 26 years old (SD 27). Eighteen percent of respondents reported a second disability with an average age of onset at 42 years (SD 23) See Figure 5.2 below for more information.

Figure 5.2. Age of Onset of Disability



The 485 participants reported 636 disabilities. Physical disabilities (165) were the most commonly reported, followed by mental illnesses (151) and developmental disabilities (125). Dementias accounted for the smallest number at 16, followed by brain injuries at 25. Aging related disabilities accounted for 40 and long-term illnesses for 73.

Eighty-nine percent of the respondents were satisfied with their place of residence. Of the 485 respondents, 288 lived in a home or apartment. Of these only 20% owned their own home while 80% lived in rental housing.

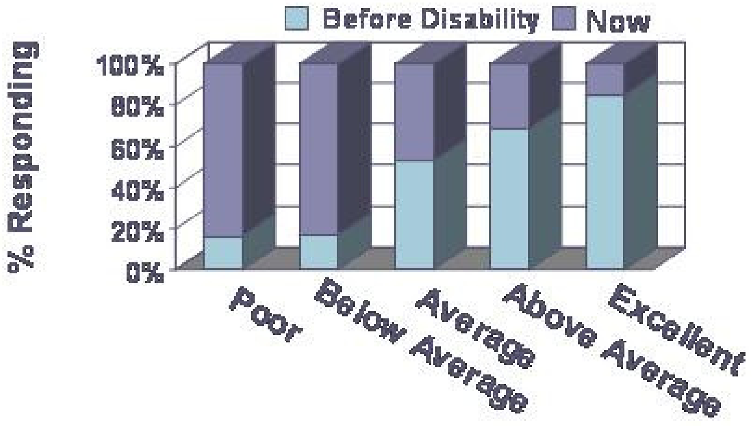
Between 159 and 209 (33 to 43%) respondents believed that their disability caused a life status change in their marriage or family, employment, living situation, medical health, psychological health, or social status. In addition, 53% of respondents believed their disability caused additional health problems, 26% believed it caused additional mental health problems, and 12% believed it caused additional oral health problems. See Figure 5.3 below for more information.

Figure 5.3. Disability Caused Life Status Change

Poverty

More than half of the respondents (54.5%) reported total household income of less than $25,000 per year. The most commonly reported total household income reported was $15,000–24,000 (20%). Just over one third of respondents reported total household income of less than $15,000 per year (34.5%).

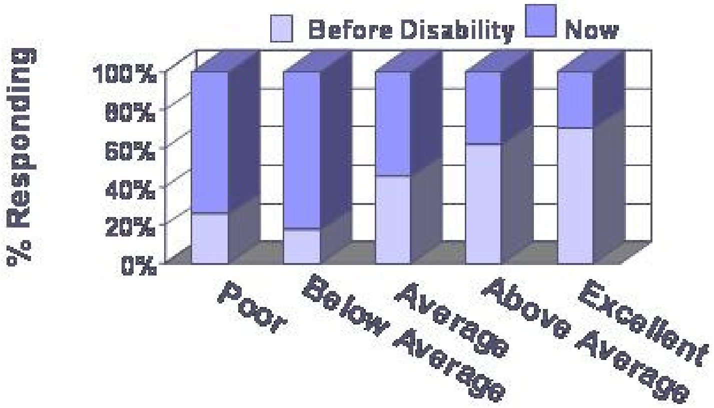
Figure 5.4. Individual with Disability Quality of Life as Remembered Prior to & After the Disability



Perceived Quality of Life

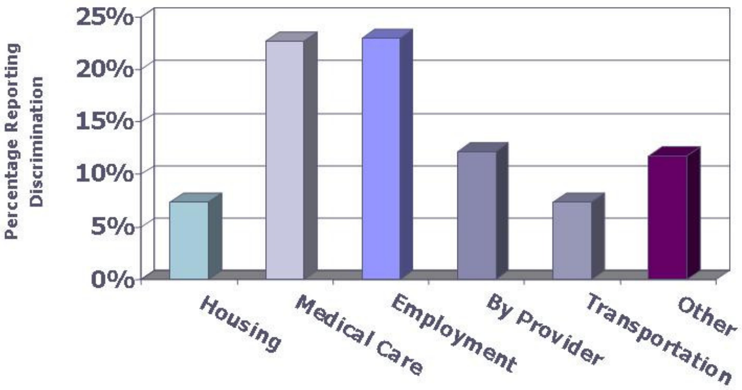
Data describing quality of life changes for the person before and after the onset of their disability showed, on average, a dramatic reversal. The largest group reported above average or excellent quality of life prior to the disability and the largest group reported a poor or below average quality of life after the onset of the disability. A similar pattern was observed among caregivers. See Figures 5.4 and 5.5 below for more information.

Figure 5.5. Caregiver Quality of Life as Remembered Prior to & After the Disability



Respondents were asked to report whether they experienced discrimination in housing, in medical care systems, by their healthcare providers, in employment, with transportation, or from any general other area. Nearly half of participants (48%, n=233) reported experiencing discrimination in at least one area as a result of their disability, accounting for a total of 410 reports across multiple life areas. It is unclear what can be understood in regard to a non-report (52%, n=252). It could be that a participant had experienced no discrimination and thus reported none, or it could be that the participant did experience discrimination but chose not to disclose their experiences. Consequently, it is only possible to draw conclusions about the 48% of participants who reported at least one experience of discrimination. See Figure 5.6 below for more information.

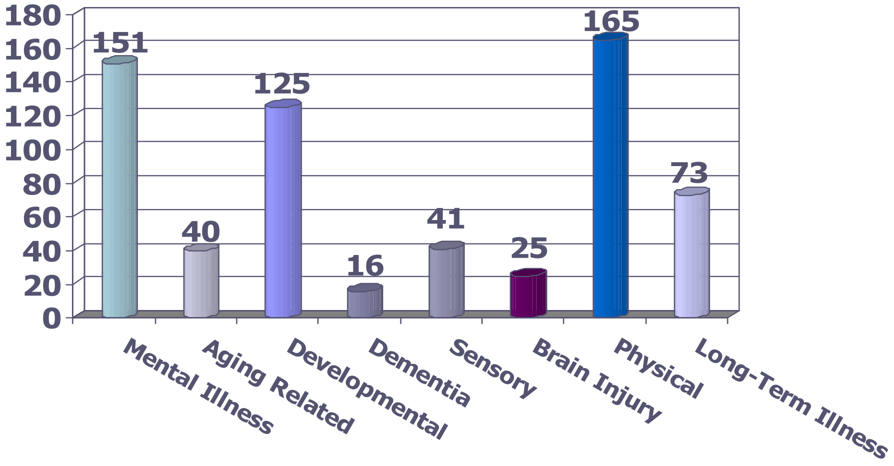
Figure 5.6. Report of Discrimination by Type of Contact



Type of Disability

Participants were allowed to report multiple disabilities. Four-hundred-eighty-five (485) people reported a total of 636 disabilities. Physical disabilities were the most commonly reported ones (n=165) with mental illness (n=151) and developmental disabilities (n=125) second and third, respectively. The graph below shows the number of disabilities reported across eight categories. It is important to note that some disabilities could have been categorized in more than one group. For example, dementia could be considered a long-term illness. Participants were allowed to self-select into the category they thought most appropriate. In some cases (less than 20), participants used the other category to insert a narrative description, which was categorized by the researchers based on similarity of category.

Figure 5.7. Types of Disabilities Represented by Respondents



Respondent Reporter by Ages

About half of the respondents answered the questions for themselves (48%, n=225) and about half (52%, n=244) answered for another person, most often (39%) a child. The current average age of the respondents was 40 years old (SD 27) with a range from 0 (infant) to 97 years old. Most of the reported disabilities were acquired after birth (72%). Half were acquired during adulthood, with 11% of these occurring after age 65.

What was the age of onset of the first disability?

- 39% reported adult (19–64 years old)
- 28% present at birth
- 22% childhood (birth–18 years old)
- 11% older adult (65 years old–over)

Below is a sampling of the types of qualitative comments respondents made. To protect the identity of the participants, some comments were merged or altered slightly, although care was taken to preserve the spirit of the comments.

- We are privately insured so I have difficulty getting the same quality of services I would get if I were on Medicaid.
- Doctors have denied me services because I was on Medicaid.

- Because my disability isn't obvious, some providers think I should not have a medical card.
- If I had a brain tumor, I would get $2 million in care; because I have a mental illness I get eight days worth of care.
- Because of my mental illness, I lost my job, went bankrupt, got divorced—what more could happen? I cannot get medical insurance for mental health.
- My job was eliminated after my employer found out my child had a disability.
- No one believes a parent.
- Airport employees refused to allow me to assist my disabled child at the security checkpoint.
- I was forced to retire after my disability.

SECTION 6: COMMUNITY DEVELOPMENT

The Idaho Real Choices Systems Change Project (Real Choices) studied the effectiveness of various strategies in assisting people of all ages with disabilities to live full, productive lives in their communities. Collaboration between Idaho State University (ISU) Institute of Rural Health (IRH) and the State of Idaho addressed five key elements (1) a Statewide Needs and Resources Assessment, (2) an Anti-Stigma Media Campaign, (3) an Economic Analysis, (4) an Effectiveness Study, and (5) a Community Development Project (CD). This report briefly discusses the accomplishments of the needs and resource assessment and anti-stigma campaign and provides recommendations for future projects utilizing the CD model.

Project Overview

Community development can be accomplished in many ways. For the purposes of this project, CD involves building bridges for people with disabilities so they can integrate into community life. Focusing on the goal of achieving successful community-based policies and plans, this CD-project included the cooperative efforts of advocates, consumers, community organizations and residents, as well as public and private agencies. Participants of the Idaho CD project were asked to identify their resources and then carry out actions that would make their community a more welcoming place for people of all ages with disabilities. The intent was to support the development of sustainable, community-based alternatives for people with disabilities wishing to live in their communities as independently as possible, while also changing the public's willingness to accept people with disabilities into their communities.

To attain the goal of making the community a more hospitable place, three types of interrelated activities were initiated. They were (1) anti-stigma media campaigns, (2) a community-based needs and resources assessment and planning project, and (3) the CD project. Quantitative research methods were used in the needs and resource assessment while both qualitative and quantitative approaches were used for the anti-stigma campaign. For the CD project, a qualitative analysis, as summarized here, was completed to outline lessons learned. The three types of activities under the grant are described briefly below. In the main body of the report, the CD activities are provided in date order, as they overlapped and supported each other. The CD project occurred in a three-county area (Bingham, Bonneville, and Jefferson Counties) in eastern Idaho around Idaho Falls. The anti-stigma campaign was presented statewide, with additional activities concentrated in the three-county area as a complement to the CD project. The needs and resources assessment was conducted statewide although data analysis for the three-county area also was completed.

Anti-Stigma Campaigns

As noted previously, there were two anti-stigma campaigns, one statewide and one concentrated in the area of the CD project in eastern Idaho. IRH facilitated design of the anti-stigma campaign with an interactive process involving a statewide Work Group of consumers, advocates, and agencies that serve them. It should be noted that the Work Group identified a number of target audiences for specific anti-stigma activities, but the mass media campaign was selected as the first priority. Due to funding, only the mass media portion was implemented. The campaign package included mass media television and radio ads along with printed posters and brochures. The purpose of the project was to create campaign materials reflecting the experiences of people with disabilities while increasing awareness among the general public about those experiences. The campaign was designed to raise awareness about community integration issues and assist the CD project to take social action. The anti-stigma mass media and print campaign was delivered to the State in 2003.

Pre- and post-population-based phone surveys in the identified media markets were conducted to assess the impact of the campaign. Every library in the state received brochures which were handed out at conferences and health fairs. Personal contacts were made with librarians in the three-county area and they were provided with additional brochures for their patrons. Posters also were designed and distributed to key stakeholders. The Idaho CareLine resource and referral phone service provided copies of brochures to those inquiring about disability issues. Toward the end of the CD project, the anti-stigma campaign was broadcast again, intensively concentrated on the eastern Idaho communities. As with the statewide campaign, pre- and post-campaign population-based surveys were conducted. While the anti-stigma campaign employed mass media to raise awareness and encourage behavior change, the posters, brochures, and CD project were aimed at local volunteers actively conducting their own accomplishments related to community-wide integration.

Needs & Resources Assessment

Part of the integrated effort was a needs and resources assessment of services and supports to people with disabilities, their caregivers, and service providers. Caregivers and consumers statewide reported on their satisfaction with living arrangements and employment, quality of life, age of onset, types of disabilities, life status change due to disability, and whether they had experienced discrimination. Data for the three-county area were tabulated generally mirroring statewide results. Data from the assessment was used to lay the groundwork for the community members participating in the CD project.

Selection & Overview of the Community Development Location

In 2003, a cooperative agreement was entered into with Jason and Associates' Idaho Falls office to carry out the CD project. Jason and Associates was the sole bidder for the Request for Proposal, which was issued statewide. Their office proposed to focus on the three-county area of eastern Idaho for the pilot CD project. Letters of support were submitted from many local leaders who were committed to the project (mayors, county commissioners, business leaders, disability-serving agencies, etc.). The contractor was responsible for convening community members and supporting them in identifying community integration needs and utilizing local resources to address those needs. Ultimately, Real Choices at IRH sought to create a lasting infrastructure of people and resources in the three-county area to support ongoing community integration. Additionally, IRH studied CD techniques and reported the project outcomes as a guide for future CD endeavors in Idaho and nationally.

Jason and Associates was charged with supporting and leading a community coalition that could identify community resources to support people with disabilities without utilizing public funds. The coalition was designed to address long-term, self-sustaining activities to identify links with the goal of addressing system-wide community integration needs of people of all ages with disabilities, long-term illnesses, and/or aging-related disabilities. Jason and Associates' role was to facilitate and lead a CD project to identify and provide community-based supports. These supports can be illustrated in the employment sector. For example, by providing community linkages (like employment opportunities), positive effects result in life factors, including self determination, community support, and employment. In addition, the local economy is enhanced because the person may become gainfully employed.

The action phase of the CD work was continued by IRH beyond the life of the cooperative agreement with Jason and Associates, which ended in August 2005. Ending in February

2006, IRH staff continued supporting CD volunteers in the three-county area to encourage changes to their community (see below for further details).

To implement the recommendations of Jason and Associates, funds from their contract were used to hire a grant writer in May 2005. Since the grant writer's work was not completed at the end of Jason and Associates' contract (August 2005), and additionally, since IRH wanted to establish self-sustaining CD in the area, Real Choices at IRH continued to support the writer's efforts through February 2006. The grant writer brought the community together to support the development of a universally accessible playground, soliciting donations from a variety of sources. Overall, approximately $64,000 was raised for the playground. In addition, land was donated by the city and other donations came from local organizations.

Summary Comments: Lessons Learned

In the two years of the project, a great deal of information was garnered. Perhaps the must stunning result of the project was a more full understanding of the difference between public participation/neutral facilitation and community development. One of the common distresses of both people with disabilities and those who provide services and supports is that much talk occurs but nothing actually changes. Certainly public participation and neutral facilitation are key aspects to system change because they permit expression of the voice of volunteers. However, the actual work of making those changes in the community is accomplished through CD, not public participation or facilitation. We believe that this piece of knowledge is so important that it alone could move many communities forward from their good-faith efforts to include people with disabilities in their processes. Processes that yield no change despite the clear desire of people with and without disabilities can be thwarted without a commitment to, and understanding of, the principles and practices of CD.

Because Real Choices was first and foremost a research study to understand the systems in Idaho and to examine how changes could occur to support true community integration, the information gathered was a complete success. However, some of the information was painfully wrought, and pointed to the flaws in how the CD project was undertaken. As noted above, the overall project did have a very positive outcome in that real changes occurred in the community; however, the true potential of a successful CD project was not realized. On balance, excellent work was done, both for the community and in learning techniques for enhancing the success of future projects. The sincere efforts of community volunteers were impressive and their dedication to the project was demonstrated.

Year 1 Activities, 2003

This section of the report is designed to provide a sequential presentation of the activities under the CD project. It offers a definition of community integration and describes Jason and Associates and volunteers' specific activities in the three-county area.

In September 2003, a Coalition Team was organized by Jason and Associates representing individuals with a broad range of backgrounds and expertise. The group included community leaders, agency providers, and those with disabilities or experiences with disabilities—such as family members. The group prepared a mission statement to guide their work: To foster self determination for all people by utilizing our community's resources. Because of their diversity and varying knowledge of disabilities, the participants initially required briefings on community integration challenges in life areas (e.g., housing, transportation, education, recreation, employment). Nearly day-long presentations were offered by local agency representatives in each of the life areas. The IRH Real Choices staff also made multiple presentations to the CD team (including presentations of the anti-stigma media campaign and needs and resources assessment data for the three-county area) to assist them in understanding the project, as well as the financial and policy issues associated with systems change.

Three public hearings were held to collect community-wide information, and all the meetings of the Team were held in public. People who were participants in the Real Choices Effectiveness Study, all of whom had a disability of some type, were invited to address the Team. Additional people with disabilities came before the Team and identified various barriers to community integration.

Volunteers with Jason and Associates organized a disability day at the regional shopping mall to raise awareness about community integration. The out-of-state company that manages the mall presented the Team with many barriers; participants attributed this to stigmatizing attitudes toward people with disabilities. The local manager expressed concern, for example, that people in wheelchairs might go through shops and knock down racks and displays. Impediments were imposed, such as requiring non-profit or volunteer organizations to obtain liability insurance. IRH supported volunteers by paying the additional fees imposed by the mall and offering its own liability insurance.

Ultimately, the Team made 12 recommendations for sustainable community changes in the areas of employment, housing, transportation, education, healthcare, and community building. Letters containing these recommendations were mailed to a variety of relevant local leaders, including mayors, county commissioners, law enforcement, transportation providers, schools, and city/county planners.

Year 2 Activities, 2004

Year 2 activities focused on taking the issues identified in Year 1 and undertook specific activities to carry out those recommendations. After an analysis of Phase I, it was determined that Phase II should focus on specific action steps. While Phase I involved the Coalition Team sending its recommendations to others, Phase II was to focus on the volunteers taking steps to begin making community change a reality. In September 2004, a Core Team was organized exclusively of people with disabilities and their families. The all-disability Core Team was created to identify specific activities to carry out the threshold work completed by the Coalition Team in Year 1. Coalition Team members were invited to participate in Core Team meetings.

The Core Team invited the general public to a series of workshops on various topics including employment, mental health, healthcare, transportation, recreation, and transitioning out of nursing homes. In May 2005 the Core Team identified the following projects:

- a universally accessible playground,
- a universally accessible fishing dock,
- a community training program to assist individuals with disabilities in joining and participating in community groups (e.g., Chamber of Commerce, Planning Commissions, library boards, etc.),
- visual/audio traffic control devices,

- a study to identify integration of available transportation services to serve individuals with disabilities,
- signs/billboards identifying the Greater Idaho Falls area (Jefferson, Bonneville, and Bingham Counties) as universally accessible.

The Core Team prioritized the projects, with the immediate goal of addressing the first three listed above. As mentioned earlier, a grant writer was hired in mid-2005. His job was to identify funding for these three priority items and mobilize local resources (financial and non-financial). Grant applications totaling $270,000 for the playground were submitted by February 2006. Funding requests for a universally accessible fishing dock were also submitted and are still pending. A local non-profit organization volunteered to spearhead the community training program although it was not operating as of February 2006.

In addressing the playground, the writer successfully partnered with a local non-profit organization representing parents of children with disabilities, the City of Idaho Falls, and other local organizations. Approximately $64,000 was raised for the project and the land was donated by the city with other donations from local organizations. Core Team members were enthusiastic about this project and its successful implementation by community partners. The additional grant applications were pending as of May 2006. The Idaho Falls coalition forged a collaborative relationship with officials and volunteers in Meridian, Idaho, where the State's first universally accessible playground is located. Over four years, Meridian organizers, starting with parents of children with disabilities, raised funds and opened Phase I of a new park. With access to information from Meridian officials, the Idaho Falls coalition was able to move more quickly to realize the goal of an accessible playground.

Action Phase

Participants were advised at the start of Year 1 and again at the start of Year 2 that IRH participation in the project would be completed in July 2005. Members of the Core and Coalition Teams were encouraged to begin the process of creating a self-sufficiency plan by the close of the Real Choices. The expectation was that it would continue after the conclusion of the grant and serve as a model for other communities. Because a self-sufficiency plan had not been completed by July 2005, IRH retained the grant writer through February 2006 to support the plan's implementation. Efforts by the grant writer were significant; contact with area mayors and other officials were made to identify methods for sustaining the Core Team's momentum.

During this period, the Core Team explored three approaches for self sufficiency.

- The first option was to encourage the group to form a non-profit 501(c)(3). This approach was unsuccessful as the volunteers on the two teams could not commit the time to running such an organization. At their September 2005 meeting, the teams determined not to pursue this approach.
- The second option was to continue operating the Core and Coalition Teams under a currently functioning non-profit or government entity's umbrella, such as the United Way or the regional office of IDHW. This required the Teams to identify a funding stream to cover operations and space under the auspices of the umbrella organization. At the September meeting 2005, this option was also abandoned.

- The third option was to form a citizen's advisory committee on disabilities for each of the three counties (Bonneville, Jefferson, and Bingham) consisting of interested volunteers. The volunteers would include the Coalition and Core Team members and involve people found by a combination of recommendations from local officials and responses to local advertisements. The local officials would select and organize the committees. The advisory committee would keep the local officials informed of needs in the disability community. The local officials would provide a place to meet and cover the minimal operating expenses. Presentation of the idea was well received by the various county commissioners and mayors; however, they did not participate in helping to find volunteers to serve on the committees nor was the committee a priority for them. The advertisement requesting volunteers was placed in the local newspapers but did not result in any volunteers. The efforts did increase awareness of needs in the disability communities. The idea would have a better chance of success if more of the local officials had remained involved from the beginning of the project. This option was abandoned in February 2006.

Although Core Team members chose not to pursue the above options, the individuals involved in the Coalition and Core Teams retained the knowledge gained during the process and still remain active in disability-related activities in the community. The universally accessible playground project united established community organizations and community resources and enhanced community awareness of the needs of people with disabilities. The impacts of this shared knowledge and experience should not be understated.

Similarly, the impact of the construction of a universally accessible playground should not be dismissed. While on the face of it, an accessible playground would only meet the needs of children and youth with disabilities, it brings with it other, less obvious, benefits that point toward sustainability and making the community more aware and receptive to people with disabilities. The playground offers the opportunity for multi-generational, family interaction for children and/or adults with disabilities in a comfortable outside setting. It provides opportunities for shared, positive, and developmentally appropriate activities. In addition to the benefits for those who use the park directly, other benefits accrue. Undoubtedly, the playground is attractive to those without disabilities, increasing the opportunities for all people to participate in a truly integrated setting. Also, the very presence of the park speaks to the importance of noticing and accepting people with disabilities. The mere presence of the park to those who pass by makes a statement that reduces the stigma and provides a message that the community perceives as integration.

Observations & Recommendations

As noted in the background portion of this report, the work of this two-year CD project crystallized the differences between public participation/facilitation and CD. Both have a significant role to play in systems change. However, public participation/neutral facilitation will not yield active change. While it is ideal for issue identification and plan development and can point to what needs to be changed and how it might be accomplished, it alone does not bring about change.

Jason and Associates is a firm specializing in public participation and neutral facilitation. The firm is inexperienced in CD as a field. As a result, the contractor applied public participation and neutral facilitation to the project rather than CD. Jason's response to the Request for Proposal indicated an understanding of CD, but the contractor did not employ CD best practices in executing the cooperative agreement. Hiring a grant writer in the final few months of the project, while helpful, provided insufficient *support to the teams and did not take the place of a CD specialist. CD requires active participation by volunteers and the Community Resource Developer (CRD) as partners to form relationships, create activities and programs, and produce concrete and measurable results. Links need to be formed between team members and the wider community, a job of the CRD.*

It is recommended that future CD projects employ a CRD from the beginning. This person must foster community leadership, guide volunteers in building community relationships, and actively encourage tactics and actions to be taken throughout the project to build on successes. This person should be trained in CD work; specifically understanding how to move a community to action on behalf of people with disabilities. Neutral facilitation and public participation methodologies, done in manners that empower volunteers, may underlie the CRD's work but should not replace it.

It is recommended that the CRD train volunteers on how to do effective CD. This training should occur at the outset of the project. Many resources are available on CD, including those designed by disability advocacy organizations. Examples include those created by the Asset-Based Community Development Institute at Northwestern University, work at the Center on Human Policy at Syracuse University, programs developed by the Center for Self-Determination, and various publications of the ARC.

The 12 areas of recommendations sent to local officials in Year 1, while helpful, were not pursued. Interviews with local officials conducted by Jason and Associates at the close of Year 1 indicated the recipients did not remember the letters and/or did not understand the role of the volunteers who sent them. In Year 2, the Core Team generally did not return to these local officials to build on relationships initiated in Year 1.

It is recommended that more local officials join active members of the project rather than send them formal letters, which can be misplaced or ignored. Letters also are ineffective when the recipients do not understand the senders/community organization volunteers' roles and responsibilities. While the mayor of the metropolitan hub of the area was a member of the Coalition Team, she attended few meetings and did not provide a substitute in her absence. A CRD could further assist by meeting with, briefing, and obtaining input from mayors or other local officials between meetings. This was a successful tactic by the grant writer in obtaining support for the accessible playground. Personal contacts by volunteers and the CRD are preferred in conveying recommendations. The results of those contacts should be reported back to the community volunteers to further inform their work.

Switching from the Year 1 Coalition Team (community) to the Core Team (people with disabilities) in Year 2 created challenges with project continuity. The Coalition Team's work in Year 1 involved education about disability issues and recommendations mailed to various local officials. The Core Team performed admirably in identifying worthwhile projects. However, once the projects were identified, the Team did not have the expertise or experience to move forward with project development.

It is recommended that the Coalition/and Core Teams be merged at the outset of the CD project, ensuring majority representation by people with disabilities and their families. Representation by people with disabilities and their families can serve as an informal tool for educating those on the team with less knowledge of disability issues, thus omitting the need for lengthy education (as was done in Year 1).

It is recommended that the CRD work hand-in-hand with the Coalition/Core Teams to encourage action-taking and results-oriented activities rather than solely education. The CRD should encourage and motivate the teams and actively pursue their recommendations into concrete community actions.

While community participation was encouraged through public hearings and meetings as well as a Disability Day at the regional shopping mall, subsequent steps furthering goals of CD were not attained. Community awareness of disability issues was raised. However, speaking at a meeting/hearing or viewing extensive displays at the mall are not equivalent to active involvement in community issues. A next step should involve recruiting the interested public to the work of community integration. An avenue for involvement in the team's work (and action steps) should be provided to those with sufficient interest to attend meetings/hearings.

It is recommended that awareness-building be part of the work of CD. The Idaho project performed this well with media relations and brochure distribution. Building on awareness, a CD project should actively recruit relevant community members to take action on behalf of the community integration movement. For example, they should identify a need for jobs among people with disabilities and take steps to encourage action by people who can offer jobs to make their places of business more welcoming to people with disabilities.

Stigma toward people with disabilities remains a serious problem. The difficulty faced with the area shopping mall is an example of this problem.

It is recommended that anti-stigma activities occur simultaneous to the CD project. Year 1 of the CD project resulted in free media among local television and radio stations as well as the IRH anti-stigma media campaign in the three-county area. Media campaigns, such as the one used in Idaho, are effective in raising awareness, but are unlikely to cause people to change their attitudes and behaviors toward people with disabilities. A multi-faceted anti-stigma effort can be successful if it includes not only media coverage but additional outreach, including public speaking by volunteers, meetings with key employers, landlords, and others in the community whose attitudes might be stigmatizing without person-to-person contact with volunteers. The anti-stigma Work Group that designed the statewide media campaign identified these and other outreach methodologies, but funding did not permit their implementation. Additionally, creation of a statewide speakers' bureau did not occur when an insufficient number of people with disabilities volunteered to join. In the three-county area, some efforts in this direction included the public workshops held in Year 2. Unfortunately, this second step was not undertaken in a significant way in the CD project. Providing volunteers with basic speaking tools (e.g., PowerPoint) and written materials could assist them as members of a speakers' bureau and sharing their stories with community groups.

Much of the Coalition Team's work in Year 1 focused on education. Many of the people included in the Coalition Team had no ties to the disability community and required education on the issues and concerns. While this is worthwhile for expanding the knowledge of those without understanding of disabilities, it created an uneven working style across the group in Year 1. In Year 2, including people with disabilities and their family members in the Core Team brought a more consistent understanding across the members. The Core Team held workshops on various topics including employment, mental health, healthcare, transportation, recreation, and transitioning out of nursing homes. Some of their activities duplicated the work of Year 1. The workshops increased public interest initially, but momentum was lost when there was no visible evidence of new discussions and no apparent implementation of the workshop's suggestions.

It is recommended that once awareness is raised (anti-stigma campaign) and input solicited (public meetings), the CD project must move forward with implementation. The CRD is the best person to carry out those functions in partnership with volunteers.

It is recommended that the need to provide education to community members about disability issues must be addressed in any similar project. Including people with disabilities and people without disabilities on a team provides this education without the need for extensive educational programs, which are time-consuming and affect attendance when concrete action steps cannot be directly linked to the educational activities. In Year 1, almost all of the monthly meetings involved an educational component, resulting in recommendations forwarded to other bodies. This delayed the Team's own progress to specific action steps.

It is recommended that specific communication tools be used to report back to the community on group action (newsletter, website, etc.). To a lesser extent, this was used in the project. Greater efforts should be used in future projects.

It is recommended that strong partnerships be formed among the volunteers and local media. While the project included the community relations director for the local newspaper, this relationship did not result in the anticipated exposure. There were many opportunities for free media which were not pursued for a variety of reasons. For example, a speaker's bureau could have taken the community integration message throughout the community.

Involvement of local agencies (public and private) is important to the overall success of a CD project. This project involved collaboration with state-level advocates in the grant and program design. The statewide group, the Community Integration Team, convened by the IDHW and the Consortium for Idahoans with Disabilities (CID), was enlisted as partners in Real Choices. IRH also reported to them at their regular meetings on the project's status. It was assumed that these statewide organizations would utilize the enthusiasm of their local representatives and consumers. However, some paid providers in the local disability community perceived the CD project as duplicative of their agencies' responsibilities, which it was not. This is a difficult issue for a CRD to address.

It is recommended that local providers be briefed in the beginning about the CD project and invited to participate. The CRD should make clear that the project is designed to support existing efforts and help develop additional community supports unavailable for reimbursement through professional providers. The CD project should not be perceived as a duplication of currently offered public and private service systems.

It is recommended that local providers be invited to participate, if not as members of the community team, as technical experts to the team of volunteers.

It is recommended that methods for communication from statewide to local advocates be established.

Attendance at meetings dwindled during the two years. In large measure, those attending were agency representatives whose time was paid by their employers. When Jason and Associates' in-house evaluator asked individuals who were not attending why, participants said they remained interested but simply could not attend all-day monthly meetings between 8 a.m. and 5 p.m. A corollary to this problem became the facilitation technique, called group memory, which was used for written minutes. It focused on themes rather than a simple recitation of action steps. This process does not promote action steps and is unlikely to be read. Minutes were not always reported back to the teams or to IRH in a timely manner.

It is recommended that at the time of participant recruitment clear time/effort expectations are provided. In addition, meetings should be as short as possible and mixed between day and evening sessions. Brief, clear minutes should be issued for those who could not attend. Posting CD materials on the web also is desirable to keep people who cannot attend involved in the work. Alternative methods of communication include email, email lists, or blogs. The CRD should serve as host and communication liaison among all parties.

Interaction with elected officials can also pay dividends when transitioning community development efforts from federal and state grants. Due to scarce resources, these elected leaders often know how to address specific needs or challenges using resources already available within their communities. Additionally, the teams may identify accessibility issues in public buildings, which can be addressed by involved local officials. In the three-county area, Jason and Associates found it challenging to obtain free, accessible meeting locations at public sites.

It is recommended that government officials (city, county, state) and/or their staff be actively involved in the CD project. They can serve as members of a team and provide information on grants, policies, and procedures. To ensure sustainability for a CD project, their involvement at all levels is critical. The CRD should meet with them regularly.

Elected leaders were enthusiastic about the CD project and initially participated. However, as time evolved, their interest waned. It should be recognized that there are great demands on their time, many are volunteers with fulltime jobs, any contributions they are willing to make may achieve good outcomes.

It is recommended that elected leaders be invited to be involved, receive regular briefings if they cannot attend organized meetings, have their expertise solicited, and have their time honored. These leaders are closely connected to their respective communities and are very often willing to support efforts to serve individuals with special needs. Their challenge is being aware of all the needs individuals with disabilities may have. Due to scarce resources, elected leaders often know how to address specific needs or challenges using resources already available within their communities. Their staff—such as planning and zoning employees—play pivotal roles in accessibility issues.

Public participation and neutral facilitation are important to CD work. However, they must be preparatory or underlie solid CD work. Additionally, in planning for a CD project, organizers must determine clear expectations for the project to guide the work of all involved.

It is recommended that all staff involved in a CD project receive training in how to accomplish successful CD. Many resources are available. Organizations with stature in the community should be involved from the start and asked to sustain specific activities as they occur. The goal is to create impetus leading to a more permanent, long-term presence of the related activities and programs in the community. The skill set and structure of the work to establish accessibility and reduce stigma for people with disabilities is no different than revitalizing a disused local downtown, expanding schools, or marketing a community. Many individuals in communities have accomplished this type of work and their skills are transferable to a CD project.

Community members often identify needs and expect government to meet them. This is especially true in the disability community, where agencies and paid providers have been employed to provide the services needed to sustain a person with a disability. Helping community volunteers understand that their work goes beyond government is a challenge. Further, CD work should focus on opportunities for action rather than addressing needs or gaps in services alone. Encouraging them to act, rather than wait for government to respond, is a similar challenge for the CRD.

It is recommended that community volunteers receive a short initial briefing on the currently available public services. During the process of work, the CD specialists or facilitators should remind them of the differing roles of government and nongovernmental/volunteer efforts. For example, Medicaid may pay for transportation, but only for medical purposes.

Children with emotional disturbances may receive accommodations in educational settings, but only for issues that affect learning. Understanding these restrictions can help volunteers better understand how government fits into the community integration picture. At the same time, government representatives should listen to volunteer's suggestions/recommendations to find innovative ways to make improvements to existing services and programs.

Locating a firm in Idaho specializing in CD was not possible. This may be true elsewhere.

It is recommended that the person serving as the CRD, if not a trained in CD, receive sufficient education in CD to bring structure and motivation to the project. This is a unique field and requires a specific skill set.

Funding for a CD project need not be expensive. Retaining an in-house CRD is likely the most cost-effective approach.

It is recommended that a CRD be hired in-house to minimize costs of a project. Consultant fees can be avoided in this way.

Members of the Coalition Team in Year 1 were frustrated that they were unable to help individual people with disabilities. They were hopeful at the outset of the project that such individuals would come before the Team so they could then provide assistance face-to-face. This was impossible for a variety of reasons, primarily respecting the privacy and confidentiality of specific individuals with disabilities. In addition, it became clear that some members of the Team did not understand their role to be that of resource development community wide vs. person-specific, this was not the thrust of the project. The volunteers' willingness to become involved in individual efforts is admirable and encouraging as it demonstrates a desire to include people with disabilities in their everyday lives. However, community-wide activities must be undertaken for the success of integration efforts provided to all people with disabilities, not just a few.

It is recommended that expectations for a team be stated clearly at the outset and the differences between community-wide development and personal interaction be demonstrated. If volunteers are expected to interact with people with disabilities on an individual basis, they will need to understand this expectation. However, if CD is the goal, volunteers should understand that they are to work on changes in systems, not necessarily changes for selected individuals with disabilities. Creating a team with people with disabilities as well as those without can better focus the group on system's issues.

SECTION 7: ANTI-STIGMA CAMPAIGN

Stigma is recognized in a significant body of research as one of the most important barriers for people with disabilities to lead productive and full lives in their communities (Haghighat, 2001; Hinshaw & Cicchetti, 2000; Kilbury, Bordieri & Wong, 1996; Crisp, 2000; Johnstone, 2001; Corrigan & Watson, 2002; Corrigan et al., 2001a; Corrigan et al., 2001b; Finlay et al., 2001; Henry et al., 2002; Crocetti et al., 1974; Link et al., 2001; Link et al., 1992; Penn et al., 1994; Rabkin, 1974; Struening et al., 2001; Bassett & Bassett, 2001; Brown & Bradley, 2002).Stigma's negative attributions toward people with disabilities are learned in childhood from strong cultural influences such as school and the media (Wahl, 1995). These messages contain assumptions that people with disabilities are to be feared, trivialized, pitied, or ridiculed (Shapiro, 1999; Wilson & Lewiecki-Wilson, 2001). People with disabilities often face hostile, oppressive environments in their communities, such as discrimination in housing and education, a lack of health and social services, and a lack of jobs and other prerequisite opportunities needed to live full, productive lives as community members (Charlton, 2000).

For many people with disabilities, stigma is a greater contributor to personal isolation than the disability itself (Kilbury, Bordieri, & Wong, 1996). Quality of life and self esteem are impacted negatively (Yanos, Rosenfeld, & Horowitz, 2001; Corrigan & Watson, 2002; Link et al, 2001). Stigma adversely influences employment potential (Bassett, Lloyd, & Bassett, 2001; Henry & Lucca, 2002) and human rights (Johnstone, 2001). These negative impacts of stigma also affect their caregivers and family members (Struening et al., 2001; Veltman, Cameron, & Stewart, 2002).

Social marketing draws on the techniques of commercial marketing to affect a social cause, in this case to lessen negative attitudes and behaviors toward people with disabilities. Philip Kotler and Eduardo Roberto define the term as: a social-change management technology involving the design, implementation, and control of programs aimed at increasing the acceptability or a social idea or practice in one or more groups of target adopters (Kotler & Roberto, 1989, p. 24). For disability, social marketing encourages people to change negative attitudes and attempts to counteract stigma, thus encouraging community integration for people with disabilities. Social marketing's ultimate goal in this context is to encourage the public to change their negative attitudes toward people with disabilities and exchange them for new, positive attitudes (Rothschild, 1999).

Methodology

The anti-stigma campaign, created under Idaho's Real Choices Systems Change Grant, was divided into four major action steps.

- Step 1: Participatory Strategic Planning: A heuristic, participatory strategic planning process designed to identify key audiences and to empower people with disabilities to create their own language and messages for the campaign.
- Step 2: Developing Materials: Development of strategic campaign materials based on the work completed by people with disabilities in Step 1.
- Step 3: Distribution and Broadcasting: Distribution of print materials and broadcast materials (television and radio) developed in Step 2.
- Step 4: Evaluation: Process and outcome evaluation relating to the campaign, created in Steps 1–3.

Step 1: Participatory Strategic Planning

People from all disability groups (physical, developmental, mental illness, and age-related) were invited to participate on a Work Group to develop the anti-stigma campaign. All were volunteers with the stated desire to address stigma as it relates to people with disabilities. The 12-member group met for 13 months (February 2002–March 2003) and follow a participatory strategic planning model created specifically to empower people with disabilities as they: studied the issue of stigma, identified key life areas where discrimination is experienced, and created or codified a language they felt best characterized their worldview. The *Social Marketing Matrix* created for strategic planning purposes followed the general tenets asserted by Paulo Freire (2003) in pedagogy designed to give voice to an oppressed people. Since stigma can result in discrimination, marginalization, and oppression of people with disabilities, the modified Freirean structure was appropriate to this population group. This process also was based on the tenets of participatory research, which as a method for empowerment—involves the people who are studied (in this case people with disabilities) as active participants in the methods, actions, and outcomes of the academic approach (Hall, 1981; Tandon, 1981). Development of the *Marketing Matrix* called on the group to identify social or economic environments where stigma is present, decide what the issues were relating to those environments, what social marketing messages were needed to change the situation, and how those messages might be delivered. Throughout the process, care was taken to record and preserve the specific language identified by people with disabilities as critical to their lives. A critical activity in Step 1 was preparation of a slogan and *Single Overriding Communication Objective* (SOCO) for the campaign: People of all ages with disabilities and long-term illnesses have abilities that contribute to their communities. They want homes, families, and friends, just like everyone else. The short slogan used in the campaign was: “Everyday People, Everyday Lives.”

Step 2: Developing Materials

The first activity in this step was to conduct a national search to determine if any other cross-disability anti-stigma campaigns had been created. No cross-disability campaigns were identified although various organizations had completed anti-stigma campaigns for one specific disability. This prompted a decision to create a unique cross-disability campaign. Using the codified language and worldview explored by people with disabilities in Step 1, IRH’s public relations and advertising professionals then began work on creative concepts. Based on the SOCO and guided by the Social Marketing Matrix, the professionals designed four English-language television ads, one English-language radio ad, and a series of Spanish-language radio Novellas. In addition, a brochure addressing stigma was produced, as was a poster for limited distribution. The ads focused on the creative concept: “We have hopes. We have goals. We are just like you.” Due to funding considerations, IRH utilized pre-existing footage provided by various Idaho disability organizations, which required the creation of ads presenting an emotional appeal with a somewhat limited ability to achieve attitude/behavior change (Kotler & Roberto, 1989). Television and radio were selected because of their ability to reach large audiences and their proven ability to successfully address attitude change (Fishbein, 2002). In addition, the Work Group of people with disabilities considered the funding limitations and decided that mass media advertising was the most expedient approach to counteract what the Work Group perceived as negative images about people with disabilities in a broad spectrum of the mainstream cultural media.

It should be noted that the Work Group also identified additional target audiences as a high priority for future social marketing approaches. Insufficient funds were available to address these specific target audiences, including medical providers, public officials, employers and coworkers, merchants, landlords, transportation providers, community and faith-based organizations, education, judicial and corrections, informal supports, and caregivers as well as paid caregivers. This information was referred to the Community Integration Committee's Education Subcommittee to be addressed as additional funding was identified (See Appendix D, Work Group: Summary and Referrals).

All campaign materials were developed based on the "words and world" of people with disabilities serving on the Work Group (Freire, 2003). Detailed minutes taken at each meeting emphasized the terms, and emotions attached to them for use in the campaign. Discussions among Work Group members focused on issues relating to the appropriate uses of words from a cross-disability content, which was unique to them. That is, some words meant different things to different people, and care was given to select words and phrases comfortable for everyone. Additionally, an initial proposal involved creating four ads concerning developmental disability, aging, physical disability, and mental illness. After discussions, it was decided not to focus on mental illness alone, but instead to create a television ad that focused on hidden disabilities, such as mental illness and brain injury. Results of these discussions were provided to a production company to prepare the radio and television ads. Scripts and rough cuts of the advertisements were presented to the Work Group for review and clarifications to ensure their intent was reflected in the final materials. A similar process was used for creating the brochure text.

When the Work Group began the Spanish Novellas, it was necessary to take a slightly different approach because no one on the Work Group spoke Spanish. Spanish-language radio Novellas were selected because of their ability to reach a broad audience of Idaho's migrant workers through this promising method of communicating to Mexican Americans (Story, 2003). Ethnic Mexican Americans wrote scripts for the Novellas and focus groups were held in Spanish to present the concepts to the target audience. The scripts were changed in areas where focus group members indicated the need. The ads were broadcast on Spanish-language radio stations during the summer growing season of July-August 2003 in the areas of southern Idaho with the state's largest population of Hispanics (U.S. Census, 2000).

Step 3: Distribution & Broadcasting

Funding for creation of the campaign came to $80,000 from Real Choices, a $10,000 donation from the Idaho Council on Developmental Disabilities (for television ad production costs), and $3,000 in-kind donation from the Idaho Transportation Department (for brochure publication). While private donations were sought to increase available funds and permit a significant statewide media campaign, a downturn in the economy did not allow corporate or other sponsors to donate to the campaign. Of the $93,000, approximately $43,000 was used to create the television and radio ads, the Spanish Novellas, the brochure and poster. To limit costs, video from previous ads by the Council on Developmental Disabilities and the IDHW were incorporated into the new campaign. Additional videotaping was needed to capture messages related to aging issues as well as physical disabilities. An analysis of possible uses of the remaining $50,000 focused on: (1) Purchasing advertising in a single market (most likely a small Idaho city); (2) Purchasing advertising in the community selected for the community development (CD) project under the grant; or (3) Identifying a way to stretch funding to permit a statewide campaign. Because it was seen as most economical, IRH entered into an agreement with the Idaho State Broadcaster's

Association to distribute the advertisements. In exchange for a $50,000 donation to the Association, its members aired the campaign ads for free although IRH did not control the times or dates when the advertisements were broadcast. The media spots aired 56,234 times over 12 months.

A total of 15,000 brochures were distributed through disability organizations, public libraries, and the Idaho CareLine—a statewide telephone center for information and referral. CareLine and Idaho State Library staff also distributed brochures at local health fairs around the state. The Work Group directed distribution of the brochures to public gathering places to ensure appropriate use of the communication tool, which was designed to raise public awareness and change attitudes relating to stigma. Additionally, another 6,000 were distributed to public libraries in the three-county area where the CD project took place.

On behalf of the Work Group, IRH attempted to establish a speaker's bureau and promote free media statewide to reinforce the paid advertising. Arrangements were made with IDHW's public information staff to issue news releases and refer callers to volunteer speakers. Only three people with disabilities volunteered to become part of the speaker's bureau, making it impossible to promote it statewide.

A second round of the radio and television ads was placed from January-February 2006 at a cost of $10,000 and covering the three-county area of the CD project. IRH contracted with a public relations firm to place the ads on television and radio stations in the three-county area.

Step 4: Evaluation

Data from the Idaho CareLine were collected. In an agreement with IRH, the CareLine collected data during the life of the statewide and three-county campaigns relating to calls regarding: disability, aging (after July 1, 2005), and mental health. It was also noted whether the calls were initiated as a result of television, radio, or brochure.

To evaluate levels of stigma, discrimination and community perceptions of people with disabilities, population-based telephone surveys were created to be delivered pre- and post-campaign (Appendix D). Quantitative research methods for evaluating stigma were utilized, including social distance and multidimensional scales and demographic data. Qualitative methods included questions relating to the person's desire to work with people with disabilities in the future and the information needed to do so effectively. Post campaign, a question focused on a person's intent to behave differently following campaign exposure. The survey was premised on research that indicates that people with disabilities experience social distance from non-disabled people that is, non-disabled people avoid, move away from, and react with nervousness and aversion to people with disabilities (Young, 1990, p. 133-134). Emory Stephen Bogardus in 1925 was the first to assert measurement of social distance when examining relations in matters of race and ethnicity (Crocetti, Spiro & Siassi, 1974). His studies address social distance measures, such as whether people are willing to marry, belong to the same club, live on the same street, work at a the same job site, or be fellow citizens of a country with people of another culture or race (Crocetti, Spiro & Siassi, 1974). Crocetti and colleagues, as well as other stigma researchers, later related Bogardus' work to people with mental illness and other disabilities. The pre- and post-campaign surveys, then, tested previous assertions that stigma relates to levels of social intimacy, and greater familiarity with people with disabilities decreases the desire for social distance. Respondents were given a 5-item Likert scale relating to their perceived levels of social intimacy relating to working or going to school with, living next door to, or living with, someone with a disability.

Another measure of attitude also is reflected in the surveys regarding R. F. Antonak's methodology relating to the multidimensional aspects of stigma. Antonak asserts that attitudes toward a group of people, such as people with disabilities, are multidimensional and hierarchical and any tool to measure them also must possess multidimensional characteristics. Accordingly, the surveys approach stigma with multidimensional measures, including social distance and access to services (jobs, education, and housing) as well as perceived levels of community discrimination and fear. Questions about perceived discrimination were compared with responses from consumers to the Needs and Resources Assessment, which was distributed to people with disabilities and their caregivers earlier in Real Choices.

The surveys were administered to a random sample of a representative number of the market size of participating television and radio stations. Roughly 486 were surveyed pre-campaign and 387 post campaign. A total of 307 were surveyed following the 2006 campaign in the three-county area. The pre- and post-campaign surveys were administered statewide to a random sample of households with telephones (and again in 2006 in the three-county area) and stratified by media market, gender, and language. A comparative analysis is reported here.

Results

Process and outcome measures were collected on each of the four major action steps cited above: Strategic Planning Process, Campaign Development, Distribution and Broadcasting, and Evaluation.

Strategic Planning Process

After a 13-month period of working together, the group was asked to respond to specific questions about the quality of the educational process and whether they believed they could affect discrimination and stigma. Members of the Work Group were engaged in a discussion in their final meeting regarding the value of the process. In addition, a confidential and anonymous survey was distributed to all members after the final meeting. A thematic analysis and frequency count of narrative survey responses was undertaken. Only five members returned the survey, with all of them indicating they were empowered by the process and would participate in similar activities, mirroring the results of the discussion in the final meeting. The analysis revealed that, of those responding: (1) all said the process was valuable because it brought people with many disabilities together toward mutual understanding; (2) all said they hoped the public would be more understanding as a result of the campaign; (3) many said they hoped that, through reduced stereotypes, greater understanding, less social isolation and greater integration for the lives of people with disabilities can occur; (4) some said that better services could result, specifically medical, transportation, workplaces, businesses, etc.; and (5) some hoped the campaign would educate the public and reduce discomfort and/or fear resulting from a lack of knowledge. Additionally, a statewide consortium of disability organizations requested monthly campaign updates, indicating goal ownership and commitment.

Development of Campaign Materials

All campaign materials were developed based on the words and world of people with disabilities serving on the Work Group (Freire, 2003). Minutes taken at each meeting emphasized the terms, and emotions attached to them, for use in the campaign. Discussions among Work Group members focused on issues relating to the appropriate uses of words from a cross-disability context. That is, some words meant different things to different people, and care was given to select words and phrases that everyone could accept. Additionally, an initial proposal involved creating four television ads concerning developmental disability, aging, physical disability, and mental illness. After discussion, it was decided not to focus on mental illness alone, but instead create a television ad that focused on hidden disabilities, such as mental illness and brain injury. Results of these discussions were provided to a production company to prepare the radio and television ads. Scripts and rough cuts of the advertisements were presented to the Work Group for discussion and clarification to ensure their intent was reflected.

An analysis of the Work Group survey results and minutes of their meetings reveals similar results relating to campaign development. As noted above, a survey of Work Group members voiced satisfaction with the strategic planning process and their new ability to advocate for each other's needs. This also is reflected in their minutes of March 31, 2003.

Campaign development success is reflected in the Work Group's satisfaction that the final campaign reflected their issues. Minutes of the June 17, 2002, meeting state that the group wanted to focus on community members' perceptions and needs in an attempt to help target adopters see the incentives/benefits to them of adopting new attitudes and behaviors. These messages are conveyed in the final document. By following the key words from the first step (Marketing Matrix) to the final ads and brochure, it is possible to see the problem-posing nature of the group's work and trace the specific terms/words/issues they identified. For example, the first step, the Marketing Matrix called for target adopters to think of people's abilities, not disabilities. This specific term carried through all the steps of codification and appears in the final ads. The concept of people with disabilities being just like you (you being the target adopter) carried through all stages to the advertisements and brochure. The list of examples is extensive.

Distribution

Analysis of distribution issues was conducted based on frequency of materials distributed to statewide and three-county audiences. Process analysis was conducted regarding distribution of campaign materials based on established Real Choices criteria. As outlined in the grant, television, radio, and Spanish-language broadcast advertisements were created as well as the brochure. The one-year campaign through the Idaho Broadcaster's Association netted 56,000 spots valued at $1.3 million, approximately $1 for every Idahoan; however exposure per person was extremely limited at just .04. Personal contact by a disability advocate and IRH staff prompted the state's largest television station (KTVB Boise), which is not a member of the Association, to broadcast the spots and extend the reach via its cable-only outlet. Numbers of spots broadcast by KTVB are not available. Attempts to encourage advocates in other parts of the state to make similar contacts with local stations and encourage additional market penetration did not occur.

The campaign in the three-county area in 2006 achieved greater market penetration than the statewide campaign. Market penetration was high; about 80% of the population of the three counties was reached an average of 8 times in the two-month period. Results indicated a 1-to-1 match (paid ads vs. donated ads) and were achieved through negotiations with the advertising agency for a total of 790 spots. While the goal had been to receive a 2-1 match, market demands at the time of the campaign (January-March) only allowed for 1-1. The total dollar value of the campaign came to more than $15,000 based on a $10,000 investment. Following the broadcast of ads, a post-campaign telephone survey was done in the three-county area, the results of which are reported below.

The Work Group was responsible for content of the brochure, which focused on educating the public about the nature of stigma and what individuals can do to address it. A total of 15,000 brochures were distributed statewide. CareLine data on calls relating to disabilities were not directly correlated to the brochure. The low response rate on the pre- and post-campaign surveys relating to the number of people who saw/heard campaign materials does not provide sufficient data to report.

Evaluation

Qualitative, process, and outcome measures were selected, including the volume of calls to the Idaho CareLine and a population-based, statewide telephone pre-post survey. Due to budget issues, no specific outcome measures for Spanish speakers were used, but Spanish speakers were included in the stratification for the population-based survey, if at a lower rate than their representation in the overall state population. Qualitative data also was collected in the phone surveys in response to questions concerning a person's willingness to work with people with disabilities and their perceptions of what they felt they needed to work with them more effectively.

CareLine Data. The media campaign instructed people to contact Idaho CareLine for more information. To measure the number of calls made in response to the Anti-Stigma campaign, Idaho CareLine workers recorded what prompted the caller to contact CareLine. While the CareLine records indicated no significant increase in inquiries callers attributed to the campaign's television, radio ads, or the brochure; total calls in these categories did increase pre and post campaign.

Considering the statewide raw data associated with calls to CareLine, total disability-related calls increased from 160 in the year before the campaign to 452 in the campaign year. Similarly, mental health calls rose to 652 from 252. No information could be obtained about increases in the aging category because CareLine did not have an aging information category prior to July 1, 2005. In the three-county area during the 2006 campaign, 17 mental health calls were received compared with seven during the same period the prior year. Disability calls dropped from nine to seven pre and post campaign.

Qualitatively, CareLine staff reported that it is not unusual for callers to indicate they have not seen materials/ads but called at the urging of a friend who had heard or seen the ads. Thus, it remains unclear whether the calls increased due to the campaign, or if the calls increased for some unrelated reason.

Pre- & Post-Campaign Surveys. Analysis of results from the pre- and post-campaign surveys revealed that there was no difference between the state and three-county surveys based on the demographics of age, gender, race or the social distance scales, life areas, and discrimination/fear. Accordingly, we can assume that there is equivalency of the statewide and three-county results prior to intervention. Thus, we analyzed all of the data together.

In the statewide stratified (market, gender, language), random sample, pre- and post-campaign telephone survey (pre n=486, post n=387; N=873), participants reported high (95%) familiarity with some type of disability. This result did not change pre- or post-campaign. Respondents said members of their communities were comfortable or very comfortable (a) living, working, or going to school in a community with people with disabilities, (n=370; 43%); (b) living next door to someone with a disability (n=520; 61%); and (c) living with someone with a disability (n=344; 41%). The post-campaign data showed no evidence of attitude change, likely due to a lack of message exposure, leaving open whether the message could cause change. Among those surveyed post campaign, only 9% (n=34) reported they had seen/heard the campaign and less than 5 people (<12%) reported an attitude change as a result. Although the number of media spots, 56,234, and their costs $1,376,630 seem large, in terms of commercial media, this is a low penetration rate for 1.36 million people.

Although anecdotal, perceptions of some individuals in the three-county area indicated that the 2006 campaign may have eased community opposition to disability issues when coupled with the CD project. Initially, the project faced community difficulties when organizing a disability awareness day at the local shopping mall. The mall manager balked at allowing the event; indicating that she and her corporate officers were concerned people in wheelchairs would disrupt business. The company required additional liability insurance from the small non-profit organizations that would set up booths at the mall. IRH, just two days prior to the event, negotiated use of the University's liability insurance and covered these additional costs. Despite this difficulty at the start of the CD project, after the anti-stigma campaign and CD activities, the project volunteers were able to gain widespread community support for an accessible playground. Specific data on these behavioral changes were not collected and the correlation is not scientific. However, members of the CD project volunteer leadership assigned the changes to the anti-stigma campaign.

Demographics. A total of 1,180 people responded to the telephone surveys (2003=486, 2004=387, 2006=307). Some imbalance relating to age among surveys was evident, although insufficient to reflect a statistical difference. A representative sample of those less than 25 years old was not achieved although representation of those over 55 was evident (30–41% depending on the survey). There was a statistical difference on the gender of those responding to the survey, with men representing at a higher rate than women (men 56%, n=658; women 47%, n=510), chi square 2=73<.001. (Remember there were no statistical differences across the three samplings.) Racial/ethnic distribution of the sample reflected the predominantly white population of Idaho. The Hispanic/Latino sample was far below that group's percentage of the total population (est. 7.9%, Census 2000) at only <5. All seven regions of the state were represented in the sample as a reflection of their proportion of the overall population.

Exposure. Essentially, all participants knew someone with a disability. Less than 1% reported not knowing someone with a disability. The most common type of disability cited was age-related (n=878, 74%). Other commonly reported disabilities were hearing (n=808, 68%) and orthopedic-related disabilities (n=759, 64%). Developmental disabilities, mental illness, chronic medical conditions, and learning disabilities were recorded by roughly 50% of the respondents in aggregate.

Perceptions of Community Social Distance. The phone survey included a subscale measure of social distance, a concept that refers to the social gap separating individuals, groups of classes, and in this case, people with disabilities. For example, high social distance is related to discomfort associated with the group that is different from the viewer. A key question to attitude change is whether or not social distance (discomfort) increases with proximity? Is a person who has high social distance in regard to people with disabilities more uncomfortable around a person with a disability than around someone without a disability? Does this vary depending on the type of disability?

To examine the relationships between (a) different disabilities the respondent had been exposed to and (b) social distance, Pearson correlations were calculated across the three phone survey samples. There was a significant correlation between the 2003 and 2006 surveys ($p<.05$), but this needs to be interpreted with caution as the r value is relatively small ($<.20$). To allow for comparisons between samples to detect the differences in the relationship between exposure and social distance, the correlation coefficients were transformed to Z scores. There was no significant difference in the relationship between exposure to people with disabilities and social distance across the 2003 to 2004 samples or in the comparison of 2004 and 2006. Between 2003 and 2004 there is no significant difference between the two samples. The comparison of the 2004 and 2006 surveys shows a significant ($p<.05$) difference in the level of social distance between the two; 2006 showed greater social distance than 2004.

Perceptions of Community Fear/Discrimination. When comparing the 2003 and 2004 results there was a significant difference ($p<.05$) between the two with 2004 showing the higher score (LESS discrimination and fear). In comparing 2004 to 2006, there was a significant difference between the two surveys. The 2006 sample showed more discrimination and fear than did the 2004 sample.

It is interesting to note that when asked in the Needs and Resources Assessment, consumers indicated they had experienced discrimination in medical care (22%); employment (21%); from their provider (12%); in transportation (7.4%); and in housing (8.5%). When asked in the pre- and post-campaign surveys if they perceived discrimination against people with disabilities in their communities, approximately 7% said they had experienced discrimination. Clearly there is a difference between individual's experiences of discrimination and the general public's perception of the presence of discrimination. The public did not perceive that discrimination is a problem but some people with disabilities did. This is an area for future research relating to community perceptions and consumer experiences.

Perceptions of Level of Difficulty by Life Areas. When analyzing 2003 versus 2004, there is a significant difference ($p<.05$) with the 2004 survey scoring higher in the life areas scale. (Does this mean more difficulty or less difficulty?) Analysis of the 2004 versus 2006 results shows no significant difference in respondents perceptions of difficulty ($p>.05$) between the 2004 statewide survey and the 2006 three county survey.

Discussion

The following discussion is based on the four campaign steps, specifically: Strategic Planning Process, Campaign Development, Distribution and Broadcasting, and Evaluation.

Step 1: Participatory Strategic Planning

The participatory process used with the Work Group in campaign design created a positive environment for people with disabilities and has great potential for use with other groups addressing disability issues. The participants praised the problem-posing/participatory process used in developing awareness, identifying audiences, and creating the campaign. The dialogue was a unique experience for them. As advocates for separate disability groups, they had not been "at the same table" before in a process that disclosed the meanings of their experiences, and said they learned by working together. Some even said if that were the only benefit of the campaign, it would have been worthwhile. This may point to the need for research to determine if the problem-posing process can be used beyond the scope of social marketing. Through development of the media campaign, they said they came to understand one another better and began advocating for others' needs. In following the Marketing Matrix, they said they also came to understand the target adopters better and, as a result, felt they designed a more effective media campaign and tool for social change. Their opinions on whether the campaign would be a strong, effective social change initiative were mixed. Some doubted whether it would achieve its broad purpose of affecting public attitudes and behaviors; others had higher hopes for the outcome.

Step 2: Developing Materials

The Work Group selected mass media for the campaign as a first stage for message development to lessen stigma among a variety of target audiences. Although the additional issues were presented to the CIC Education Committee (See Appendix D, Anti-Stigma Work Group: Summary and Referrals), no action was taken to address them. Funding under Real Choices did not provide for additional activities to reach these added target audiences. Future research/campaigns in Idaho should build on the Marketing Matrix and address the specific target audiences identified by the Work Group. In addition, the contents of this matrix may be helpful in other states as they determine where to start anti-stigma efforts.

The media campaign was designed as an emotional appeal. As such, its ability to impact behaviors may be limited (Kotler & Roberto, 1989). However, we have been unable to adequately address impact because of the campaign's low penetration resulting from limited funding. Additional research might focus on utilizing focus groups and a structured interview for pre- and post-campaign exposure. Additionally, future campaigns should utilize pre-campaign focus groups of target adopters to ensure the messages are relevant and appropriate to identified audiences.

Qualitative comments from the pre- and post-campaign surveys were reviewed for thematic content. Response categories included: needing more information, understanding available services, understanding life experiences when discriminated against, and learning how to act in respectful ways. Additionally, some respondents indicated that personal interaction with people with disabilities was desired and that such exposure could generate additional understanding and compassion. The response from one individual sums up this thematic category and mirrors the message of the ad campaign: "that they [people with disabilities] are real people with real feelings." Another respondent said. "We need to operate out of love, not fear." Additional research could focus on the effectiveness of face-to-face interactions among people with and without disabilities as it relates to attitude/behavioral change.

Step 3: Distribution & Broadcasting

Supplementing the media campaign with face-to-face interaction among people with disabilities and their communities held great promise for extending market penetration without additional expenditure. Despite efforts to establish a speaker's bureau and coordination with the public information staff at the IDHW to implement it, an insufficient number of people with disabilities volunteered to join the speaker's bureau to make the concept viable statewide.

Step 4: Evaluation

The most notable finding of this study was the lack of attitude change revealed in pre- and post-campaign surveys. This can be attributed to a variety of causes. First, the campaign reach was extensive (statewide) but the actual audience for the ads was limited for a variety of reasons. For example, insufficient funding impacted campaign penetration, such as the number of times an individual could be exposed to the message. The agreement with the Idaho Broadcaster's Association, while economical within the funding limits of the grant, did not afford IRH any control over time or date of placement, which can significantly affect the impact of the message. Not all stations in the state are members of the Association, most notably the largest television station in the state. Additionally, northern Idaho is in the Spokane, Washington, television market, and the significant expense of paying for advertising to the entire Spokane market in order to reach the small northern Idaho portion of that market was not viable.

Impact on Spanish-speaking Idahoans was not fully explored due to time, funding, and the migratory nature of the Mexican American population. Surveys were conducted in English and administered via telephone, which could impact these results. The radio ads for Hispanics were placed over the noon hour during the summer months, when migrants take a lunch break. They infrequently have pen and paper available at that moment to jot down the CareLine number. Therefore, we are unable to determine whether there was an attitude/behavior shift in this population. However, focus groups of the target audience utilized in campaign development indicated high satisfaction with, and expectations for, the Novellas.

The nature of the campaign, presented in a cross-disability framework, created barriers to both development and evaluation. The lack of any previous cross-disability ad campaign that could be utilized and adapted for Idaho created financial hurdles; this was anticipated by IRH. Due to a lack of funding and the inability to obtain corporate sponsors in the economic downturn, the Idaho project could not afford to film a new campaign. This forced development to focus on existing materials from other organizations and incorporate these pre-existing materials into the television ads. Because of the content of the previous ads, the Real Choices advertisements were limited to an emotional appeal. Additionally, while the pre- and post-campaign surveys asked respondents whether they had contact with people of different disabilities, we did not explore the nature of those relationships. With that additional information, we could have determined whether the depth of the relationships impacted social distance and discrimination. This is an area for future research.

The IRH surveys (pre and post campaign) focused on demographics, familiarity, social distance, multidimensional attitude, and (post) campaign knowledge and impact. This may have created ambiguity in the results. For example, the social distance measures utilized by previous researchers included a detailed analysis of multiple variables relating to social intimacy. The social distance questions IRH pulled three variables out of the existing literature. Although those variables reflected different levels of social distance (go to school/work with, live next door to, live with), utilizing a more extensive list of variables may have produced different results. Anecdotally, with the high level of familiarity, some respondents indicated they already were living with someone with a disability, especially those in older age ranges. Finally, the surveys asked respondents to say if the social distance variable occurred in their community. This was done to ensure respondents did not give us the right answer if we had asked if they themselves were comfortable with the levels of social intimacy. While the literature supports this change, it is impossible for us to state whether the respondents placed social distance between themselves and people with disabilities. Also impacting this was the high level of familiarity with people with disabilities. In summary, one would expect high familiarity to correlate to low social distance, high levels of comfort and lower levels of discrimination/fear; indeed, this is what we found.

Section References

Bassett, J., Lloyd, C., & Bassett, H. (2001). Work issues for young people with psychosis: Barriers to employment. *British Journal of Occupational Therapy, 64*, 66-72.

Brown, K., & Bradley, L.J. (2002). Reducing the stigma of mental illness. *Journal of Mental Health Counseling, 24*, 81-87.

Corrigan, P. W., Edwards, A. B., Green, A., Diwan, S. L., & Penn, D. L. (2001a). Prejudice, social distance, and familiarity with mental illness. *Schizophrenia Bulletin, 27*, 219-22.

Corrigan, P. W., River, L. P., Lundin, R. K., Penn, D. L., Uphoff-Wasowski, K., Campion, J., et al. (2001b). Three strategies for changing attributions about severe mental illness. *Schizophrenia Bulletin*, *27*, 187-195.

Corrigan, P.W., & Watson, A.C. (2002). The paradox of self-stigma and mental illness. *Clinical Psychology: Science & Practice*, *9*, 35-53.

Crisp, R. (2000). A qualitative study of the perceptions of individuals with disabilities concerning health and rehabilitation professionals. *Disability and Society*, *15*(2), 355-367.

Crocetti, G. M., Spiro, H. R. & Siassi, I. (1974). *Contemporary attitudes toward mental illness.* Pittsburgh, PA: University of Pittsburgh Press.

Finlay, W. M., Dinos, S., & Lyons, E. (2001). Stigma and multiple social comparisons in people with schizophrenia. *European Journal of Social Psychology*, *31*, 579-592.

Fishbein, M., Cappella, J., & Hornik, R. (2002). The role of theory in developing effective antidrug public service announcements. In W. D. Crano & M. Burgoon (Eds) *Mass media and drug prevention: Classic and contemporary theories and research* (89-117). Mahwah, NJ: Lawrence Erlbaum Associates.

Friere, P. (2003 [1970]). *Pedagogy of the Oppressed* 30th ed. New York: Continuum.

Haghighat, R. (2001). A unitary theory of stigmatisation: Pursuit of self-interest and routes to destigmatisation. *British Journal of Psychiatry, 178*, 207-215.

Hall, J. W., Ewing, A., & Tinzmann, M.B. (1981). Phonetic coding in dyslexics and normal readers [Comment/Reply]. *Bulletin of the Psychonomic Society*, 17(4):177-178.

Henry, A.D., & Lucca, A.M. (2002). Contextual factors and participation in employment for people with serious mental illness. *Occupational Therapy Journal of Research*, *22*, 83S-84S.

Hinshaw, S.P., & Cicchetti, D. (2000). Stigma and mental disorder: Conceptions of illness, public attitudes, personal disclosure, and social policy. *Development and Psychopathology*, *12*, 555-598.

Idaho Broadcasters Association (2003). Ad Hoc Report. Boise, ID.

Idaho CareLine (2006). Ad Hoc Report. Boise, ID.

Johnstone, M. (2001). Stigma, social justice and the rights of the mentally ill: Challenging the status quo. *Australian & New Zealand Journal of Mental Health Nursing*, *10*, 200-209.

Kilbury, R., Bordieri, J., & Wong, H. (1996, April-June). Impact of physical disability and gender on personal space. *Journal of Rehabilitation*, *59-61*.

Kotler, P., & Roberto, E. (1989). *Social marketing: Strategies for changing public behavior*. New York: Free Press.

Link, B. G., Cullen, F. T., Mirotznik, J. & Struening, E. (1992). The consequences of stigma on persons with mental illness: Evidence from the social sciences in stigma and mental illness. In P. J. Fink & A. Tasman (Eds.), *Stigma and mental illness* (pp. 87-96). Washington, DC: American Psychiatric Press.

Link, B.G., Struening, E.L., Neese-Todd, S., Asmussen, S., & Phelan, J.C. (2001). Stigma as a barrier to recovery: The consequences of stigma for the self-esteem of people with mental illnesses. *Psychiatric Services*, *52*, 1621-1626.

MacStravic, S. (2000). The missing links in social marketing. *Journal of Health Communications, 5*, 255-263.

Penn, D. L., Guynan, K., Daily, T., Spaulding, W. D., Garbin, C. P., & Sullivan, M. (1994). Dispelling the stigma of schizophrenia: What sort of information is best? *Schizophrenia Bulletin*, *20*(3), 567-574.

Rabkin, J. (1974, Fall). Public attitudes toward mental illness: A review of the literature. *Schizophrenia Bulletin*, *10*, 9-31.

Rothschild, M. L. (1999). Carrots, sticks, and promises: A conceptual framework for the management of public health and social issue behaviors. *Journal of Marketing*, *63*(4):24-37.

Shapiro, T. (1999). 'Between empathy and judgment': Comment. *Journal of the American Psychoanalytic Association, 47*(2): 390-395.

Story, C. (2003). Social Marketing. Unpublished Master's Thesis. Boise State University.

Struening, E.L., Perlick, D.A., Link, B.G., Hellman, F., Herman, D., & Sirey, J.A. (2001). Stigma as a barrier to recovery: The extent to which caregivers believe most people devalue consumers and their families. *Psychiatric Services, 52,* 1633-1638.

Tandon, R.K. (1981). A study-habit survey among home science under-graduates. *Child Psychiatry Quarterly, 14*(1): 26- 31.

U.S. Census. (2000). U.S. Census. Retrieved July 28, 2006, from http://www.census.gov/popest/states/asrh/tables/SC-EST2003-03/SC-EST2003-03-16.pdf

Veltman, A., Cameron, J.I., & Stewart, D.E.(2002). The experience of providing care to relatives with chronic mental illness. *Journal of Nervous and Mental Disease, 190*(2): 108-114.

Wahl, O.F. (1995). *Media madness: Public images of mental illness.* New Brunswick, NJ: Rutgers University Press.

Wilson, J., & Lewiecki-Wilson, C. (Eds.). (2001). *Embodied rhetorics: Disability in language and culture*. Carbondale, IL: Southern Illinois University Press.

Yanos, P. T., Rosenfeld, S., & Horowitz, A.V. (2001). Negative and supportive social interactions and quality of life among persons diagnosed with severe mental illness. *Community Mental Health Journal, 37*(5): 405-419.

Young, I.M. (1990). *Justice and the politics of difference*. Princeton, NJ: Princeton University Press.

SECTION 8: EFFECTIVENESS STUDY

Purpose

Real Choices Effectiveness Study is a research project that incorporated research on long-term care transition and diversion, shifting toward community integration. Participants were asked to allow us to test, plan, implement, and follow along to see how the process developed. In exchange, participants had access to the usual resources that can be acquired through means like waivers and the ordinary Medicaid and Medicare services, but were also provided access to things that could be negotiated through the community development (CD) project and the research study as a whole. In addition to learning how to initiate the transition or diversion, the study examined how to sustain the transition or diversion in order to aid participants in maintaining or improving their lifestyles following termination of the research study.

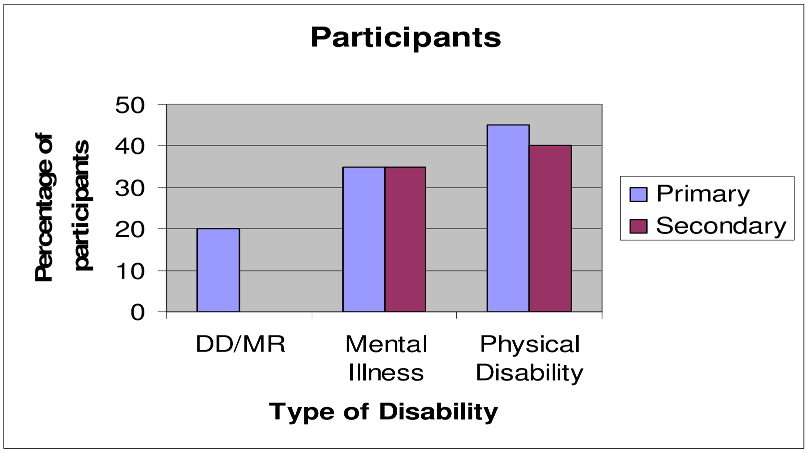
To this end, the study attempted to foster the fundamental values of self-determination, personal responsibility, and support to individuals, families, and communities as they sought their greatest level of self-reliance. It was recognized that all participants have strengths and abilities to contribute to the process of community integration and the effective use of services. Hence, the role of the Idaho State University (ISU) Institute of Rural Health (IRH) staff in this project was to help individuals focus on their strengths and abilities while fostering self-reliance in self-directed life goals. The study was centered in the community where all integration activities were taking place, Idaho Falls, Idaho.

Participants

Individuals of any age with a disability, long-term illness, or issue of aging were eligible for participation based on their desire to increase community integration and personal independence in a self-directed way. Participants (n=23; 57% female & 43% male) were recruited by public advertisement, word of mouth, and flyers sent to existing service providers located within a tri-county area with approximately a 50-mile radius centered around the community development location. This is considered the “service area” of the community. Participants were recruited in their normal constituent group; for example, a family dyad or couple, or an individual and his or her personal attendant were all oriented to the project information and participation commitments during the informed consent presentation. Following this presentation of information, potential participants (adult and children) were given a minimum of 24 hours to review the informed consent before volunteering or refusing participation (see informed consent for adults and the informed consent for adolescents or children in Appendix G). In the case of a child participant or adult guardianship, participants were offered the opportunity to show their assent. If they did not assent, they did not participate in the study, even if the guardian requested participation.

Participants ranged from age 6 to 78 (mean=39; SD=22.8). Disability types were classified into three broad categories: developmental disabilities/mental retardation (DD/MR), mental illness, and physical disabilities. Participants reported the following broad categories of primary disability: DD/MR (20%), mental illness (35%) and physical Disability (45%; see Figure 8-1). Secondary disabilities were reported by 75% of respondents with 40% reporting additional physical impairment and 35% reporting secondary mental illness. Participant data were also categorized by age sets: child (ages 1–17), adult (ages 18–54), and older adult (55+). The total number of participants in each age category included 6 (26%) children, 9 (39%) adults, and 8 (35%) older adults.

Figure 8-1. Reported Participants' Primary & Secondary Disability Categories



Of the 23 participants, 17 (75%) reported a secondary disability. This does not include secondary disabilities that are of a similar category (e.g., more than one physically disabling condition).

Figure 8-2. Reported Family Members' Primary & Secondary Disability Categories

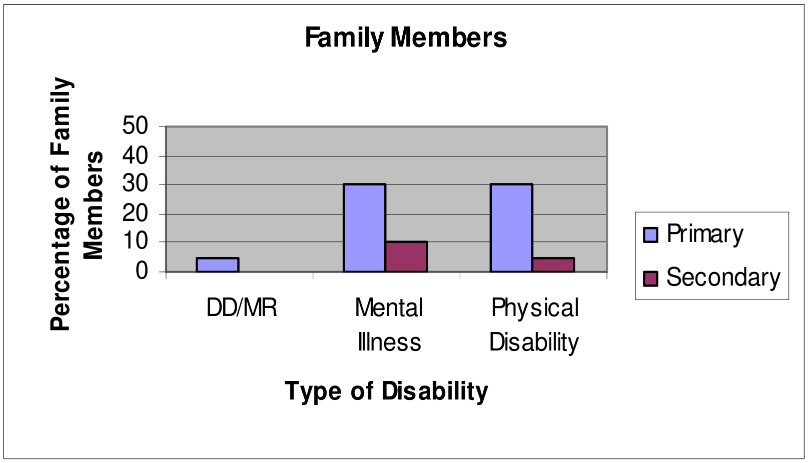


Table 8-1. Strategy & Grouping of Data Points Across Time

Original Variables	Process	New Variables
Baseline	Equals	Baseline
Time 1	Equals	Planning and Development
Time 2 – next to last implementation visit (as available)	Mean	Implementation
Last implementation visit and closing visit	Mean	Closing
First Follow-Up	Equals	Initial Follow-Up
All Follow-Up	Mean	Long Follow-Up

Of the 23 participants, 7 resided alone and 16 lived with at least one family member (mean=3; maximum 7). Family members residing with participants consisted of 48 individuals, including 17 (35%) children, 23 (48%) adults, and 8 (17%) older adults. Of the 48 family members, 81.2% also were experiencing at least one disabling condition (see Table 8-1). Seventy-five percent of family members who also served as primary caregivers for participants were reported to have at least one disability themselves.

Procedure

Data Collection

The self-directed psychosocial rehabilitation protocol *Pragmatic Problem Solving: A Method for Case Management* (PPS) was used for this project. This protocol has been used to monitor overall well-being of participants in multiple clinical and community trials, including the Veterans Affairs Cooperative Study, CSP #420, Group Treatment for Post Traumatic Stress Disorder, and the ISU HSC-approved Five Feathers Project. At enrollment, a comprehensive functional and community integration assessment was completed using a variety of assessment measures (described below).

Following enrollment and the initial baseline functional assessment, functional assessment results were reviewed with participants prior to PPS plan development in order to support the plan development. Upon review of these functional assessment results with the participants, self-directed integration plans were cooperatively developed based on functional strengths and identified difficulties. Goals were developed across the following life domains as appropriate to each individual's needs and preferences: housing, transportation, employment/volunteer work, education, health/medical, and leisure/recreation.

Subsequent to plan development, graduate research assistants coordinated informational, service, accommodation, and financial supports necessary to implement integration plans. Participants were engaged in designing and implementing their community integration plan (CIP) over a 7–15 month period. Any services needed based on plan implementation were reimbursed from Medicaid/Medicare when available; however, if a service was not covered under the current system, but part of the plan being studied, services were paid by other sources, including grant money, or through a no-cost community resource.

While engaging in these activities at enrollment and each subsequent month, participants reported information, via phone or video phone, relevant to personal quality of life (BDI-2, LSR, & SF-12; described in detail below). A minimum of monthly progress tracking of PPS goal accomplishments (as identified in the integration plan) was possible during case manger contact. A trained graduate researcher completed monthly data collection with each participant or with parents/guardians when the participant was a minor or supervised by a legal guardian as an adult. Despite the initial plan of equal one-month interval data collection, data collection intervals were not typically equal for a variety of reasons (e.g., participant illness, participant travel, staffing changes, holidays, etc.). Each "monthly" evaluation had the specific date of data collection noted in order to address unequal intervals during analysis. In addition to baseline and exit assessments, a maximum of 18 monthly evaluations were completed and up to eight follow-up data points.

Additional contacts were made as necessary to support integration efforts and completion of plan objectives. Upon completion of the plan or project, a second functional assessment (repeat of baseline measures) was completed. At least one follow-up data collection similar to the "monthly" data was taken following exit. Follow-up data was collected a minimum of one time post-exit and as many as eight times.

Assessment Measures

Given the level of diversity possible with participants, a number of psychological assessment tools were identified as options to be selected based on the participant's age appropriateness. However, all participants were assessed at a minimum using the Community Integration Questionnaire (CIQ), Pragmatic Problem Solving semi-structured interview (PPS), and Life Status Review (LSR). Child participants, or those who could not complete the measures on their own behalf due to their disability, were completed by a parent or guardian. Adolescents and all adults completed BDI, SLES, and SF-12 measures, but children did not due to age inappropriateness. Parents of children and adolescents completed a CBCL questionnaire at baseline and exit, but this measure is not used for adult participants.

***Beck Depression Inventory* (BDI)**. The BDI-II is a 21-item measure designed to assess the severity of depression in adults and adolescents by self-report or clinical interview administration. The items are devised to correspond with the diagnostic criteria for depression found in the *Diagnostic and Statistical Manual of Mental Disorder IV* (APA, 1994). Widely used in research literature as a measure of depression, the BDI-II is reported to have alpha coefficients ranging from .86–.92 with various clinical and non-clinical populations.

***Child Behavior Checklist* (CBCL).** The CBCL is a 113-item measure to be completed by parents regarding multiple areas of child's functioning in comparison to age-based norms. Parents endorse items on a 3-point scale reporting how true the statement is regarding their child. Results yield eight syndrome scales: Anxious/Depressed, Withdrawn/Depressed, Somatic Complaints, Social Problems, Thought Problems, Attention Problems, Rule Breaking Behavior, and Aggressive Behavior. The measure is designed to be used with children ranging in age from 6–18.

***Community Integration Questionnaire* (CIQ).** The CIQ consists of 15 items relevant to living, loving, and working, or more formally: home integration (H), social integration (S), and productive activities (P). It is scored to provide subtotals for each of these, as well as for community integration overall. The basis for scoring is primarily frequency of performing activities or roles, with secondary weight given to whether or not activities are done jointly with others, and the nature of these other persons (for example, with/without TBI).

***Consumer Experience Inventory* (CES).** The CES E/D was designed to provide State officials with information about program participants' experience with the services and supports they receive under the 1915(c) waiver program, the Medicaid HCBS waivers. This measure was intended for use with elderly and non-elderly adults with physical disabilities. The CES provides indicators of program participants' experience in four domains: Access to Care, Choice and Control, Respect/Dignity, Community Integration/Inclusion.

***Pragmatic Problem Solving* (PPS).** The PPS is a semi-structured interview that is based on the overall PPS psychosocial model to evaluate strengths and weaknesses for individuals and their family members across a variety of life domains.

***Life Status Review* (LSR).** The LSR (Stamm & Rudolph, 1998) can be applied like a structured interview as used in a clinical visit (e.g., with seriously mentally ill, 20–30 minutes) or as a self-report checklist (5–10 minutes). Both administrations augment clinical or research information and summarize a broad perspective on a person's overall situation. This may provide information about potential support systems, stressors, or problem areas in the person's social environment. By tracking both problems and good things, individuals and clinicians can identify areas of strengths and weaknesses. Scales across life areas range from –2 (very bad) to 0 (normal for this person) to +2 (very good). The patient LSR data has an overall alpha of .93 (M=.06, SD 7). The alpha reliabilities of the subscales range from .67–.96. The inter-scale correlations range from .14–.70 with all but 3 less than r=.45.

***SF-12 Health Survey* (SF-12).** The SF-12 is a shortened version of the SF-36. It is designed as a general measure of health focusing on eight health concepts: physical functioning, role-physical, bodily pain, general health, energy/fatigue, social functioning, role-emotional, mental health, and change in health. The SF-12 can be self-administered or given in an interview format and only requires about two minutes to complete. Scoring is broken into a Mental Component Summary (MCS) score and a Physical Component Summary (PCS) score that discriminate how individuals differ in their mental and physical health status. Test-retest reliability was reported to be .89 for PCS and .76 for MCS.

***Stressful Life Experiences Screening* (SLES).** The SLES (Stamm et al, 1996) is intended for use with adults in order to identify life events that may be stressful or important in a person's life. The 20-item screening tool draws on the extant literature and DSM-IV criteria for Post Traumatic Stress Disorder, not for the purpose of diagnoses, but for identification of potentially negative experiences. Particularly sensitive to change over time, the SLES is reported to have alpha reliabilities for internal consistency of at least .70 with various populations.

Data Analysis

As mentioned in the methods, data were collected at different time-points in the intervention. There were 27 possible time-points including at baseline (1), while in the study (18), closure (1), and follow-up (8). Neither all of the possible 18 time-points while in the study nor were the 8 follow-up time points always collected or necessary. The scores from these times were combined in a way to simplify data analyses and make a more meaningful presentation (see Table 8-1). As mentioned before, not all participants required all 18 of the intervention data points or 8 follow-up visits, so the mean of the available scores were used for both of these stages of the intervention. To account for possible increase in distress during preparations for closing/exiting the study, the average of the next to last implementation score and the closing score was used as the closing measure. For those measures completed only at baseline and exit (i.e., SLES, CIQ), only the two data points were available for pre- and post-intervention comparison.

Results

Stressful Life Experiences Screening (SLES)

The SLES (Stamm et al, 1996) was administered to adolescent and adult participants at initial baseline (intake) and again at closing in order to provide a measure of trauma exposure and possible change in current stressfulness over time.

Participants reported experiencing between 2 and 15 extremely stressful events, with an average of experiencing 7 events (SD=3.8). Three stressful events most frequently endorsed by participants included the following: "Witnessed or experienced a serious accident or injury" (n=13, 57%), "Witnessed or experienced a life-threatening illness" (n=16, 70%), and "Witnessed or experienced the death of a close friend or family member" (n=18, 78%). Results from participants' current stressfulness ratings at initial intake compared to current stressfulness at closing indicate a significant reduction in the amount of stress experienced

(t_{14}=-3.970, p<.001). This suggests that over the duration of an individuals' participation in the Real Choices Effectiveness Study the amount of current stress related to experiencing an extremely stressful event in their past significantly declined.

The three stressful events endorsed by a majority of participants were also the events that evidenced the greatest reduction in reported current stress. Fifty-two percent of participants reported a reduced amount of current stress in relation to two previous experiences, including "witnessing or experiencing a serious accident or injury" and "witnessing or experiencing a life-threatening illness." For the individuals who "witnessed or experienced the death of a close friend or family member," 69% reported a reduction in current stress related to that experience at exit. See Table 8-2 for change from intake to exit in current stressfulness ratings for the 20 stressful experiences.

Table 8-2. Change in Stressfulness from Initial Intake to Closing by SLES Items

Stressful Experience	*Number/Percent*	*More Stress*	*No Change*	*Less Stress*
Witnessed/experienced natural disaster	Number	>5	13	9
	Percent	>5	56.5	39.1
Witnessed/experienced man-made disaster	Number	0	17	6
	Percent	0	73.9	26.1
Witnessed/experienced serious accident or injury	Number	>5	10	12
	Percent	>5	43.5	52.2
Witnessed/experienced chemical/radiation exposure	Number	0	22	>5
	Percent	0	95.7	>5
Witnessed/experienced life threatening illness	Number	>5	10	12
	Percent	>5	43.5	52.2
Witnessed/experienced death of spouse or child	Number	0	17	6
	Percent	0	73.9	26.1
Witnessed/experienced death of close friend or family member	Number	0	7	16
	Percent	0	30.4	69.6
I, a close friend or family have been kidnapped/taken hostage	Number	0	22	>5
	Percent	0	95.7	>5
I, a close friend or family have been victim of terrorist attack/torture	Number	0	23	0
	Percent	0	100	0
Been involved in war or lived in area of war	Number	0	23	0
	Percent	0	100	0
I have seen/handled dead bodies	Number	0	21	>5
	Percent	0	91.3	8.7

Stressful Experience	***Number/Percent***	***More Stress***	***No Change***	***Less Stress***
I feel responsible for injury/death of person	Number	0	19	>5
	Percent	0	82.6	17.4
I have been, or have witnessed someone, attacked with a weapon	Number	>5	18	>5
	Percent	8.7	78.3	13
As a child, I was hit, spanked, choked or pushed hard enough to cause injury	Number	0	18	>5
	Percent	0	78.3	21.7
As an adult, I was hit, spanked, choked or pushed hard enough to cause injury	Number	>5	17	>5
	Percent	>5	73.9	21.7
I witnessed someone else being choked, hit, spanked, or pushed hard enough to cause injury	Number	>5	13	9
	Percent	>5	56.5	39.1
As a child or teen, I was forced to have unwanted sexual contact	Number	0	15	8
	Percent	0	65.2	34.8
As an adult, I was forced to have unwanted sexual contact	Number	0	18	>5
	Percent	0	78.3	21.7
I have witnessed someone else being forced to have unwanted sexual contact	Number	0	20	>5
	Percent	0	87	13

Analysis of Complex Interactions

Because of the limited number of individuals available (N=18) for analyses and the preliminary nature of these analyses, the complex interactions were evaluated in separate analyses. To account for the fact that multiple analyses were being conducted, a Bonferroni adjustment was used to evaluate the significance of the results. The adjustment using an alpha of .05 required an adjusted significance level of .004. In the results, significance values of greater than .004 will be reported as >.05 adjusted. To maximize the use of the data, analyses were conducted using SAS using a mixed factorial procedure, starting with the most complex interaction (time x sex x age group x disability type) and moving to the 2-way interactions. Time has 6 levels (as defined in Table 8-2). Age group was originally defined as having three levels: child (0–17 years), adult (18–54 years), and older adult (55+ years). Disability type also has 3 levels (DD/MR, mental illness, physical disability) which were defined as the participants' primary disability. When more than one category of disability was reported, primary disability was determined by clinical judgment following the baseline assessment as to the disability currently presenting the most significant functional impairment. Differences in N included in analyses represent missing data due to participant withdrawal (e.g., moving residence, discontinuing participation, etc.).

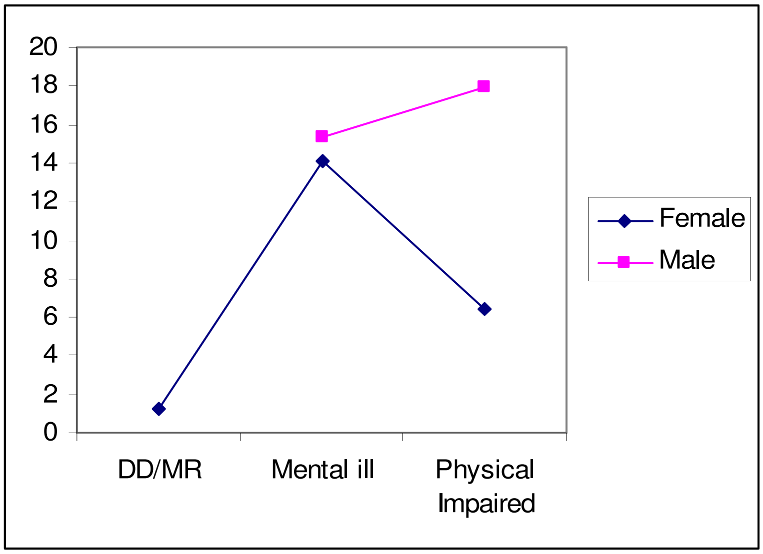
Beck Depression Inventory (BDI). Because the BDI was not administered to young children there were fewer than persons in the youngest age group; therefore, they were combined with the 18–54 age group, making it a 16–54 age range. There were no significant 4-way or 3-way interactions (adjusted $p<.05$). There was a significant Disability group by Sex interaction (adjusted $p<.05$, $F(4,13)=7.33$, $p=0.0026$). The means are presented below (Table 8-3). As shown in Figure 8-3, males in the physically disabled category reported significantly higher levels of depressive symptoms than females with a physical disability.

Table 8-3. Beck Depression Inventory Means; 2-Way (Sex x Disability) Interaction

Gender	*Primary Disability*	*Estimate*	*Standard Error*
Female	DD/MR	1.2038	2.8751
Female	Mental Illness	14.0420	1.7830
Female	Physically Impaired	6.4758	1.9384
Male	Mental Illness	15.3633	2.8751
Male	Physically Impaired	17.9702	2.6246

N=18

Figure 8-3. Beck Depression Inventory; 2-Way (Sex x Disability) Interaction

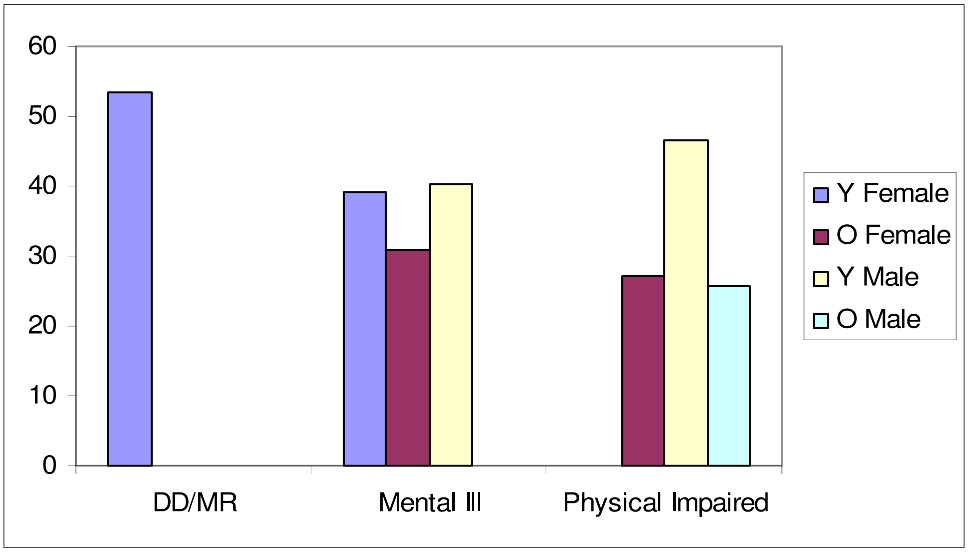


SF-12 Physical Component. Because the SF-12 was not administered to young children and there were fewer than five people in the youngest age group, they were combined with the 18–54 age group making it a 16–54 age range. The 4-way interaction was not significant. There was one significant 3-way interaction, Age group by Sex by Disability type (adjusted $p<.05$, $F(6,11)=7.88$, $p=0.0018$). The means are presented in Table 8-4. To examine this interaction we look to the means by sex/age group for the disability types (Figure 8-4).

Table 8-4. SF-12 Physical Health 3-Way Interaction (Sex x Disability x Age Group)

Gender	*Primary Disability*	*Age Group*	*Estimate*	*Standard Error*
Female	DD/MR	16–54	53.3586	3.7158
Female	Mental Illness	16–54	39.0418	3.1404
Female	Mental Illness	55+	30.8966	3.5428
Female	Physically Impaired	55+	27.1578	2.5052
Male	Mental Illness	16–54	40.2356	3.7158
Male	Physically Impaired	16–54	46.4452	3.7158
Male	Physically Impaired	55+	25.6802	8.3087

Figure 8-4. SF-12 Physical Health 3-Way Interaction (Sex x Disability x Age Group)



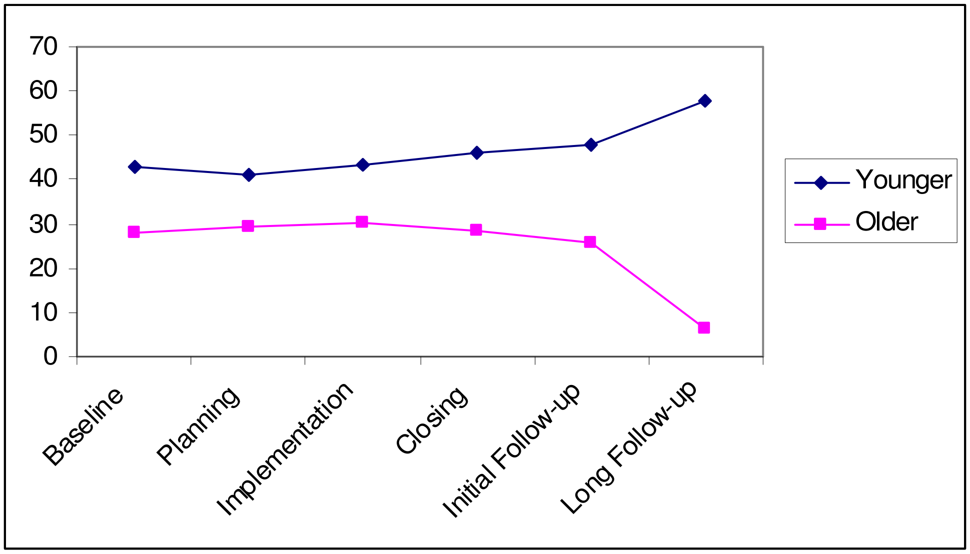
The major contributor to this interaction is the empty cells. Aside from the empty cells, persons in the mental illness disability group remained stable on SF-12 physical scores across time, regardless of their sex/age group. However, looking at those in the physically disabled category the young males scored higher on the SF-12 physical component than other sex/age classifications within this disability type (Figure 8-4). This suggests that young males with physical disabilities feel less impaired by their physical limitations than other older males.

Next, examining the two-way interactions, there was a Time by Age group interaction (adjusted $p<.05$, $F(11,50)=3.03$, $p=0.0036$). The means are presented in Table 8-5 below and the interaction is presented in Figure 8-5. As shown in the figure, the younger group remains stable across the duration of the project and increases on this measure towards the end of the project, while the older group, who also remained stable during participation in the project, decreases at the end.

Table 8-5. SF-12 Physical Health 2-Way Interaction (Time x Age Group)

Time	*Age Group*	*Mean Estimate*	*Standard Error*
Baseline	Younger	43.0512	4.0521
Baseline	Older	27.9349	4.5304
Planning	Younger	41.0457	4.0521
Planning	Older	29.2827	4.8432
Implementation	Younger	43.5411	4.2713
Implementation	Older	30.3046	5.7306
Closing	Younger	45.9459	4.8432
Closing	Older	28.5235	5.7306
Follow-Up Immediate	Younger	47.8377	4.8432
Follow-Up Immediate	Older	25.9289	5.2313
Follow-Up long	Younger	57.6553	12.8139
Follow-Up long	Older	27.6307	6.4070

Figure 8-5. SF-12 Physical Health 2-Way Interaction (Time x Age Group)

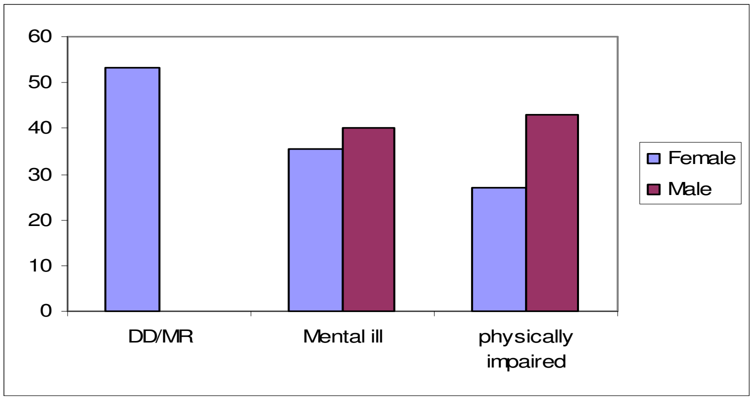


There also was a Sex x Disability group interaction (adjusted *p*<.05, *F*(4,13)=9.002, *p*=0.0010). The means are presented in Table 8-6. Again there are missing data that contribute to the significance of the interaction (Figure 8-6). There is a similar pattern with those who have mental illness as the primary disability, the males and females do not differ on the SF-12 physical subscale. However, for the participants within the physical disability category, the males scored higher on the SF-12 physical component than the females, indicating males feel less impaired by their disabling condition than do females.

Table 8-6. SF-12 Physical Health 2-Way Interaction (Sex x Disability)

Gender	*Primary Disability*	*Mean Estimate*	*Standard Error*
Female	DD/MR	53.3586	3.8675
Female	Mental Illness	35.4579	2.4460
Female	Physically Impaired	27.1578	2.6074
Male	Mental Illness	40.2356	3.8675
Male	Physically Impaired	42.9844	3.5305

Figure 8-6. SF-12 Physical 2-Way Interaction (Sex x Disability)



There was also a significant Age group x Sex interaction (adjusted $p<.05$, $F(3,14)=11.01$, $p=0.0006$). The means are presented in the table below. The males evidenced a greater difference between age groups than did females (Figure 8-7).

Table 8-7. SF-12 Physical 2-Way Interaction (Sex x Age Group)

Gender	*Age Group*	*Mean Estimate*	*Standard Error*
Female	Adult	45.0071	2.5201
Female	Older adult	28.4041	2.1492
Male	Adult	43.3404	2.7607
Male	Older Adult	25.6802	8.7300

The final significant 2-way interaction was the Disability group x Age group ($F(4,13)=12.11$, $p=0.0003$). The means are presented in Table 8-8 below. There are no participants with DD/MR in the older group (Figure 8-8). There is little difference between the younger versus the older age groups on the SF-12 physical scores for those in the mental illness category. A larger difference exists between age groups for those in the physically disabled category.

Figure 8-7. SF-12 Physical 2-Way Interaction (Sex x Age Group)

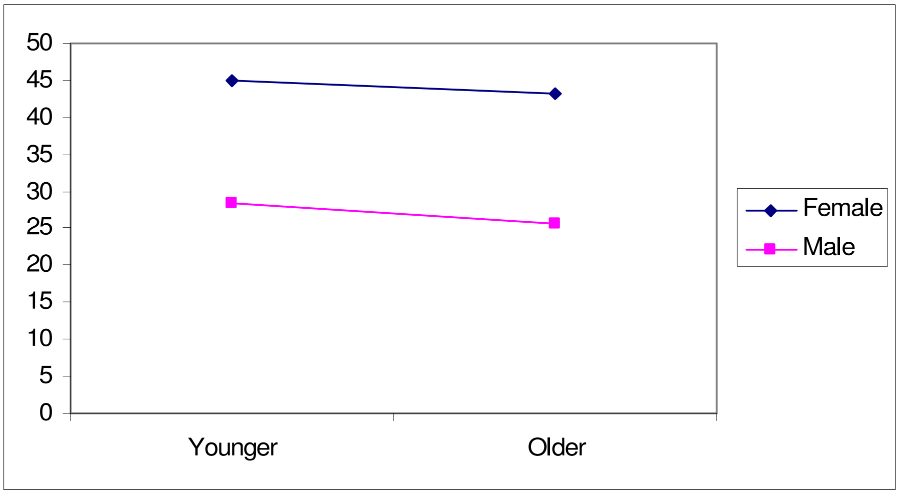
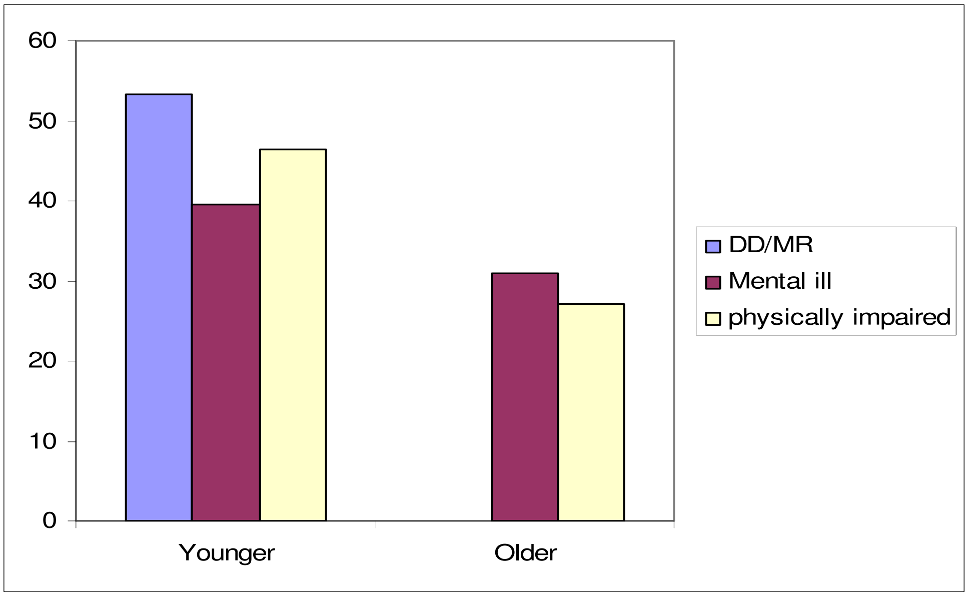


Table 8-8. SF-12 Physical Health 2-Way Interaction (Disability x Age Group)

Primary Disability	*Age Group*	*Mean Estimate*	*Standard Error*
DD/MR	Younger	53.3586	3.6675
Mental Illness	Younger	39.5392	2.3674
Mental Illness	Older	30.8966	3.4968
Physically Impaired	Younger	46.4452	3.6675
Physically Impaired	Older	27.0347	2.3674

Figure 8-8. SF-12 Physical Health 2-Way Interaction (Disability x Age Group)

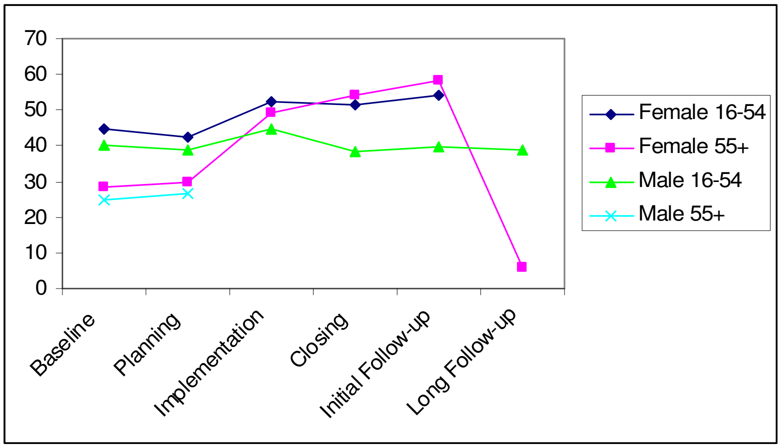


SF-12 Mental Component. Because the SF-12 was not administered to young children there were only two persons in the youngest age group therefore they were combined with the 18–54 age group, making it a 16–54 age range. The 4-way interaction was not significant (*p*<.05 adjusted). There was a 3-way interaction that was significant: Time x Sex x Age group

Table 8-9. SF Mental 3-Way Interaction (Time x Sex x Age Group)

Time	*Gender*	*Age Group*	*Estimate*	*Standard Error*
Baseline	Female	55+	28.4043	4.5692
Baseline	Female	18–54	44.8890	4.9353
Baseline	Male	55+	24.6490	12.0890
Baseline	Male	18–54	40.2944	6.0445
Planning	Female	55+	29.7113	4.9353
Planning	Female	18–54	42.5746	4.9353
Planning	Male	55+	26.7114	12.0890
Planning	Male	18–54	38.7523	6.0445
Implementation	Female	55+	49.4424	5.4064
Implementation	Female	18–54	52.4942	5.4064
Implementation	Male	18–54	44.6387	6.0445
Closing	Female	55+	54.4189	5.4064
Closing	Female	18–54	51.6638	6.0445
Closing	Male	18–54	38.5525	6.9796
Initial Follow-Up	Female	55+	58.2986	4.9353
Initial Follow-Up	Female	18–54	57.5450	6.0445
Initial Follow-Up	Male	18–54	39.8056	6.9796
Long Follow-Up	Female	55+	55.6224	6.0445
Long Follow-Up	Male	18–54	38.8722	12.0890

Figure 8-9. SF-12 Mental 3-Way Interaction (Time x Sex x Age Group)

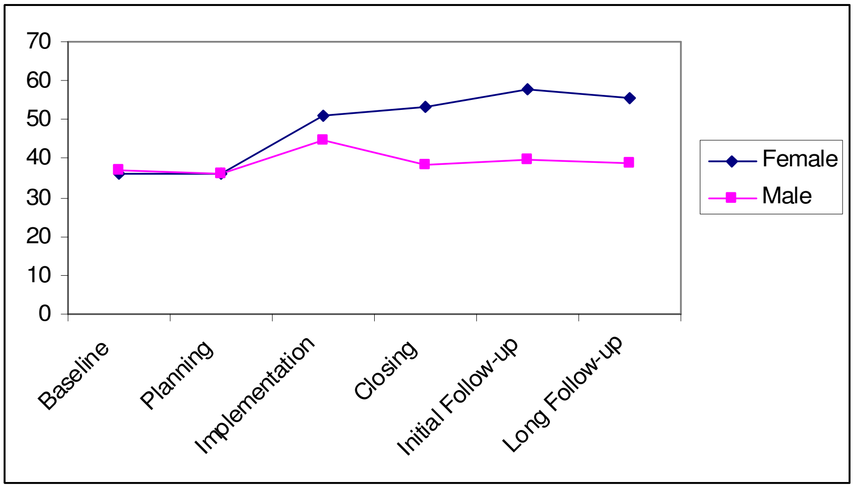


interaction. The means for this interaction are in the Table 8-9 below. As seen in Figure 8-9, there are empty cells, for example, males 55+ only have Baseline and Closing data. Among the data that do exist, at the Long Follow-up time point there is a drop in scores for the females in the 55+ group. Prior to the Long follow up, the males in the 16–54 group were stable on this scale while the females in the 55+ group steadily improved. Of the 2-way interactions for the SF-12 Mental Score, the Time x Sex interaction was significant (adjusted $p<.05$, $F(11,50)=3.48$, $p=0.0012$). The means are reported in the table below. Figure 8-10 demonstrates the 2-way interaction. As seen below, the males remained fairly stable over time while the females' scores climbed as the intervention progressed (i.e., over time).

Table 8-10. SF-12 Mental 2-Way Interaction (Time x Sex)

Time	*Gender*	*Estimate*	*Standard Error*
Baseline	Female	36.0126	3.4714
Baseline	Male	37.1653	5.5975
Planning	Female	36.1429	3.6132
Planning	Male	36.3441	5.5975
Implementation	Female	50.9683	3.9580
Implementation	Male	44.6387	6.2582
Closing	Female	53.1944	4.1721
Closing	Male	38.5525	7.2264
Initial Follow-Up	Female	57.9972	3.9580
Initial Follow-Up	Male	39.8056	7.2264
Long Follow-Up	Female	55.6224	6.2582
Long Follow-Up	Male	38.8722	12.5164

Figure 8-10. SF-12 Mental 2-Way Interaction (Time x Sex)

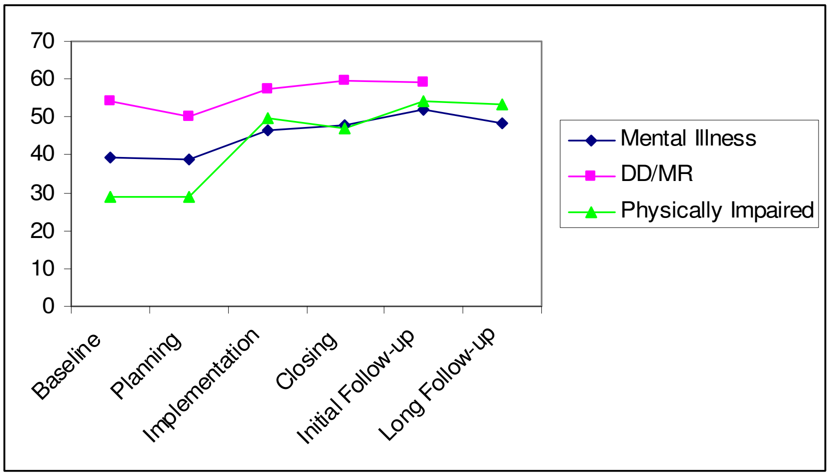


There was also a significant Time by Disability Type interaction ($F(16,45)=2.79$, $p=0.0035$). The means are reported in Table 8-11 below. The graph in Figure 8-11 indicates that participants in the physical disability category showed the greatest change starting out below individuals in the mental illness category, and ending with a score that was slightly higher. Participants with physical disabilities evidenced a steady increase in SF-12 Mental Component scores over the duration of the project, while the individuals in the other two disability categories remained stable over time.

Table 8-11. SF-12 Mental 2-Way Interaction (Time x Disability)

Time	*Primary Disability*	*Estimate*	*Standard Error*
Baseline	Mental Illness	39.4133	4.3978
Baseline	DD/MR	53.9684	8.7955
Baseline	Physically Impaired	28.8435	4.3978
Planning	Mental Illness	39.0332	4.3978
Planning	DD/MR	50.2166	8.7955
Planning	Physically Impaired	28.9624	4.7014
Implementation	Mental Illness	46.4734	4.7014
Implementation	DD/MR	57.1864	8.7955
Implementation	Physically Impaired	49.7101	5.5628
Closing	Mental Illness	47.9800	5.0781
Closing	DD/MR	59.5572	8.7955
Closing	Physically Impaired	46.8533	6.2194
Initial Follow-Up	Mental Illness	51.8114	5.0781
Initial Follow-Up	DD/MR	59.0785	8.7955
Initial Follow-Up	Physically Impaired	54.0726	5.5628
Long Follow-Up	Mental Illness	48.4657	12.4387
Long Follow-Up	Physically Impaired	53.2240	6.2194

Figure 8-11. SF-12 Mental 2-Way Interaction (Time x Disability)

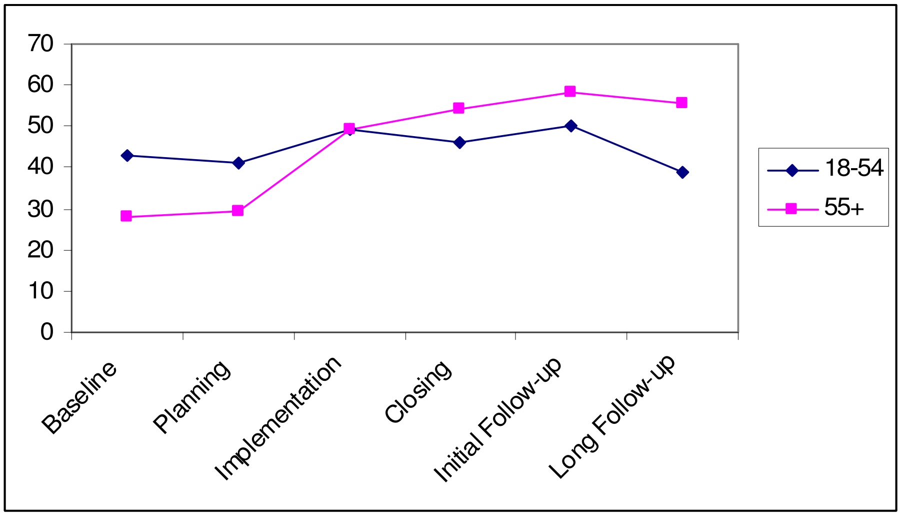


Finally, there was a significant Age Group x Time interaction (*F*(11,45)=3.64, *p*=0.0010). The means are displayed in Table 8-12 below. Examination of Figure 8-12 reveals that the younger group remained fairly stable throughout the project and follow-up, while the older group showed a steady increase in SF-12 mental scores over time.

Table 8-12. SF-12 Mental 2-Way Interaction (Age x Time)

Time	*Age Group*	*Estimate*	*Standard Error*
Baseline	55+	27.9349	4.2859
Baseline	18–54	43.0512	3.8334
Planning	55+	29.2827	4.5818
Planning	18–54	41.0457	3.8334
Implementation	55+	49.4424	5.4213
Implementation	18–54	49.0029	4.0408
Closing	55+	54.4189	5.4213
Closing	18–54	46.0447	4.5818
Initial Follow-Up	55+	58.2986	4.9489
Initial Follow-Up	18–54	49.9424	4.5818
Long Follow-Up	55+	55.6224	6.0612
Long Follow-Up	18–54	38.8722	12.1223

Figure 8-12. SF -12 Mental 2-Way Interaction (Age x Time)



Life Status Review **(LSR).** There were no significant 4-way, 3-way or 2-way interactions on the LSR Medical, Health, Financial, Housing, Transportation, Employment, School, Social, or Leisure subscales. On the Legal subscale, there was a significant 4-way interaction (*p*<.05 adjusted, *F*(54,2)=24.18, *p*<.0001). These are very difficult to interpret given the small sample size. The significant result is more than likely caused by an outlying score related to the physically impaired/male/0–17 age group where at the initial follow-up the mean is 2, quite different from all of the other means. There was one significant 3-way interaction on the Legal subscale (p<.05 adjusted, $F(42,37)=23.35$, p<.0001), Time x Disability Type x Age group. This is again difficult to interpret, since it appears as though the significant difference is caused by the outlying score at follow-up for the 0–17-year-old individuals with physical disabilities. There were no significant 2-way interactions.

Significant interactions were also found with the Substance Abuse subscale of the LSR. The 4-way interaction Time x Sex x Disability Type x Age group was significant (p<.05 adjusted, $F(55,27)=8.58$, p<.0001). One 3-way interaction, Time x Disability Category x Age group was also significant (p<.05 adjusted, $F(43,39)=13.38$, p<.0001) and there was a single 2-way interaction that was significant, Disability Type by Age group (p<.05, $F=(7,15)=6.60$,p=0.0011). All of these significant interactions are the result of one individual who scored a 2 on follow-up interviews. No further interpretation of these interactions is discussed to protect the anonymity of the participant. There are no significant interactions at any level when the analyses includes only baseline to closing.

Main Effects of Analyses for Age, Disability Category, & Sex

The data were analyzed using SAS mixed factorial procedure for the analyses of mixed designs. This procedure utilizes all of the data available. Because of the limitation of the

Table 8-13. Means by Age Group

	Age Groups			Statistics	
Variable	**0–17**	**18–54**	**55+**	**F**	**P**
BDI Total	8.68	12.89	10.02	0.97	0.402
SF-12 Physical	56.21	41.17	28.25	25.47	<.0001
SF-12 Mental	54.08	43.03	43.43	2.30	0.135
LSR Medical	0.05	-0.21	-0.30	4.69	0.021
LSR Health	0.12	-0.15	-0.17	3.13	0.066
LSR Finance	0.03	-0.12	-0.34	4.23	0.029
LSR Housing	0.17	0.08	0.02	0.57	0.576
LSR Tran	0.11	0.01	-0.18	1.86	0.182
LSR Employment	0.23	-0.05	0.01	4.18	0.030
LSR Legal	0.05	-0.01	0.00	0.85	0.444
LSR Substance Abuse	0.06	-0.02	-0.04	2.02	0.160
LSR Social	0.15	0.12	0.17	0.09	0.915
LSR Leisure	0.14	0.00	-0.04	1.02	0.380
CIQ Prod	5.21	2.86	1.73	17.60	<.0001
CIQ Home	3.94	5.79	5.07	1.32	0.288
CIQ Social	7.57	6.57	7.07	0.48	0.626
CIQ Total	**16.80**	**15.08**	**13.87**	**1.01**	**0.382**

number of participants, the main effects for each of the four measures (BDI, SF-12, LSR, and CIQ) were examined in separate analyses, creating 17 total main effects. With a Bonferroni adjustment for multiple comparisons, significance level on the 17 tests has to reach $p<.003$ to be significant at an alpha of .05.

Differences by Age. Two of the measures demonstrated a significant main effect of age. The physical component of the SF-12, $F(2,15)=25.47$, $p<.0001$, showed a significant difference across age groups with older adults having the greatest level of difficulty in this domain (child mean=56.21, adult mean=41.17, and older adult mean=28.25). There were also significant differences between age groups on the Productivity subscale of the CIQ, $F(2,20)=17.60$, $p<.0001$, with the child category showing the highest levels of productivity (child mean=5.21, adult mean=2.86, older adult mean=1.73). Both remained significant after the Bonferroni adjustments were made to the alpha level to account for the multiple tests. The means and significance levels for all 17 main effects are presented in Table 8-13.

Differences by Disability Type. Using the Bonferroni alpha adjustment criteria described above, only one of the tests was significantly different across disability type. The

Table 8-14. Means by Disability Type

	Disability Type			***Statistics***	
Variable	**DD/MR**	**Mental Ill**	**Physically Impaired**	***F***	***p value***
BDI Total	1.20^{a}	14.41^{b}	10.53^{ab}	7.36	0.006
SF-12 Physical	53.36^{a}	36.82^{b}	32.74^{b}	9.49	0.002
SF-12 Mental	56.00	44.45	40.99	4.45	0.030
LSR Medical	-0.02	-0.23	-0.17	1.27	0.301
LSR Health	0.03	-0.12	-0.07	0.63	0.542
LSR Finance	-0.08	-0.04	-0.29	2.37	0.119
LSR Housing	0.02	0.11	0.11	0.19	0.829
LSR Transportation	-0.07	-0.12	0.12	1.45	0.258
LSR Employment	0.03	0.10	0.03	0.31	0.738
LSR Legal	0.00	-0.01	0.04	0.61	0.553
LSR Substance Abuse	0.04	0.04	0.04	0.69	0.513
LSR Social	0.17	0.06	0.22	1.2	0.323
LSR Leisure	-0.15	0.06	0.11	1.79	0.192
CIQ Prod	5.10^{a}	3.00^{b}	2.35^{b}	6.75	0.006
CIQ Home	2.93	4.89	6.16	4.07	0.033
CIQ Social	6.70	7.13	7.24	0.13	0.882
CIQ Total	**14.73**	**15.02**	**15.69**	**0.11**	**0.900**

Physical Component of the SF-12 was significantly lower, F(2, 15)=9.49, *p=.002,* for individuals with physical disabilities, as would be expected (mean=32.74, SD 4.16; see Table 8-15). Post hoc analyses indicate that participants in the DD/MR disability category score significantly higher than participants in both the Mental Illness and Physical Disability categories, which were not significantly different from one another (means=53.36, 36,82, and 32.74, respectively). Different superscripts denote a significant (*p*<.05) difference in a post hoc test adjusted for multiple comparisons.

It could be argued that given the preliminary nature of these data a less conservative approach would also be acceptable. If alpha were set at .01 then there are two others that reach significance, BDI total, F(2,15)=7.36, p=.006, and the CIQ Productivity subscale F(2,15)=6.75, *p*=.006. Post hoc analyses on the BDI data indicate that individuals within the Mental Illness category have significantly higher depression scores than the other two disability groups, and the physically impaired individuals reported significantly greater depression scores than individuals in the DD/MR category (means=14.41, 10.53, and 1.20, respectively). Within the CIQ productivity subscale, post hoc analyses revealed that those in the DD/MR category reported significantly higher levels of productivity than both the Mental Illness and physical disability categories, which did not differ from one another (means=5.10, 3.00, and 2.35, respectively).

Differences by Sex. Participants included 13 females and 10 males. When using time as a repeated measure, there were significant differences across time on the BDI, F(1, 16)=9.97, *p*=.0061 (see Table 8-3), with males scoring higher on the BDI over time. There were no other significant differences across time on any of the other measures. The main effect of sex was then examined at each individual time point. As with the overall analyses there were limited main effects of sex at the different times; however, some differences were found.

There was a significant difference in sex on the BDI at initial follow-up, F(1,11)=5.20, *p*=0.0436, with females reporting significantly less depressive symptoms than males (means=4.2 and 12.67, respectively). The majority of differences by sex were on the LSR. A significant effect of sex was found on the leisure scale of the LSR, F(1,21)=4.80, *p*=0.0400, with males reporting significantly higher scores on this life domain at baseline (means=0.200 and -0.46, respectively). There also was a significant sex difference in the LSR health scale at planning and development, F(1,20)=6.57, *p*=0.0186. Again, males reported significantly greater scores than females (means=0.20 and -0.33, respectively). A significant sex difference in the LSR Social scale was found at closing, F(1,15)=5.34, *p*=0.0355, with males reporting significantly lower scores than females (means=-0.03 and 0.26, respectively). The transportation scale of the LSR was also significantly different for males and females at exit, F(1,20)= 5.64, *p*=0.0277, with males scoring higher than females (means=0.45 and -0.25, respectively). On the SF-12, there was only one significant difference found. At initial follow-up, females scored significantly higher than males (means=57.99 and 39.81, respectively) on the SF-12 Mental scale F(1,11)=12.35, *p*=0.0049.

Discussion

In order to examine the first research question of whether or not people with disabilities are better off when integrated into the community, it is important to clearly understand where project participants started. The demographic statistics of this study are almost as compelling as the intervention results. These demographics strongly suggest that integration of individuals with disabilities is a complex process for a number of reasons.

First, it is likely that the person is coping with more than one disability across categories. Fully three-fourths of participants reported a disability of a secondary category (e.g., a physical disability *and* mental illness, developmental disability *and* physical disability). This does not take into account that most participants had multiple diagnoses with differing functional impairments within the primary disability category. For example, it was common for an individual to be experiencing multiple medical conditions (i.e., congestive heart failure, orthopedic impairment, and visual impairment), which all have unique functional limitation and integration issues. The implications in regard to the complexity of intervention are critical. Individuals with disabilities are facing multiple barriers to integration created by the interplay of multiple disabling conditions. It brings into question whether the social policy system—which is moving more towards an individual waiver program based on the identification of a single disability—captures the needs or the nature of integration for most individuals needing assistance.

The second issue identified by demographics is the informal support system or the formal or informal families of persons with disabilities. Integration is a systemic issue. Isolation and non-integration impacts the family and its functioning in multiple ways, and successful integration, especially in rural areas, frequently pivots on informal family support due to the lack of formal resource options. Participants in this project reported that their family members were already taxed with demands from their own disabilities. We were stunned by the finding that 81.2% of family members have at least one functionally impairing disability, a rate fully 8 times higher than the national statistics (U.S. Census, 2000). This included 75% of primary caregivers, which speaks to the need to address the family system rather than the individual when focusing on integration needs. If primary caregivers had been unable to provide support and care, many of the participants would have been facing institutional care. Even so, 19% of participants residing with family members reported that they had been forced to choose whether they or their spouse would receive Medicaid coverage due to income issues. As a result of their decision, primary caregivers were frequently going without medical coverage or mental health treatment when issues arose.

It is clearly problematic for primary caregivers with disabilities, who are arguably more in need of support than other caregivers and do not have access to basic medical, dental and mental health care. Not only will their functional status decline more quickly, but their ability to support their loved one while remaining community-based will ultimately be impaired. This Medicaid policy could easily lead to a save-a-nickel-to-spend-a-dollar situation. Costs avoided by denying coverage to the primary caregiver will quickly be consumed by the increased care needs of their spouse when primary caregivers are no longer able to provide assistance. The potential loss of quality of life and personal integration for the primary caregiver also suggests that their ability to remain productive and contribute to society will be severely impaired without access to medical and mental healthcare.

The third implication of demographic information is relevant to the project's measures of trauma exposure and continuing traumatic stress. Participants' reported an average lifetime exposure rate to A1 Criterion events of 7, fully three times the rate of the general public. Many of these events were reported as having ongoing traumatic stress impact during baseline. This suggests that the consideration of trauma treatment and trauma triggers during community integration activities may be critical to integration success and to improved quality of life. Traumatic stress may contribute unique barriers to community integration, such as avoidance of certain community facilities or situations for trauma reasons when in fact accessing those very facilities and activities may be central to the success of integration. These trauma-based barriers must be recognized and addressed in order for integration to be fully successful and in order to prevent increased vulnerability of additional exposure to potentially traumatic events.

Are people with disabilities better off when integrated into a community?

With this foundation in place, the answer to the question of whether individuals with disabilities are better off when integrated into the community is a resounding "yes" based on the data collected across the project. Mental health data strongly support this conclusion.

Preliminary results from the CIQ suggest that individuals experienced improved integration with participation in the project. It should be noted that, while the CIQ is "state of the art" in integration measures, it has significant measurement weaknesses both psychometrically and in interpretation. Given these measurement problems, qualitative information is especially important in reconciling interpretation of quantitative data. Within that context of qualitative information, participants reported greater independence in daily living skills and greater life productivity as a result of integration activities.

There were steady improvements in SF-12 Mental component scores across time, indicating reduced functional impairment in emotional functioning with participation. There were some differences in mental health for males and females. For example, females reported greater mental health gains than males in SF-12 scores. This was also evident in lower BDI scores, indicating less depression for females at follow-up. Finally, the mental health improvement with relation to traumatic stress is impressive. While it is unclear whether the significant drop in overall traumatic stress is a byproduct of the project's support of general mental health treatment, time, or other integration factors, it is clear that participants experienced a significant reduction in ongoing traumatic stress symptoms while participating in the integration process.

Life status and satisfaction scores also support the claim that individuals are better with integration. While most LSR scores did not demonstrate statistically significant improvements across time, the reported scores were either stable or slightly improved across domains. This is clinically significant when one considers that one would anticipate deterioration across time for individuals with chronic disabilities. As functional impairments increase with anticipated deterioration, all life status domains tend to be impacted, and this was not the case for participants. The lack of statistical significance in life satisfaction scores is likely related to the small number of participants, which reduces statistical power to detect significant differences. Without a control comparison group, it is somewhat uncertain whether this view is accurate, but it appears that maintained stability (e.g, not "losing ground") is an indication of success with this population across time. There are some statistically significant mental health differences between genders worth noting. Females did report higher social satisfaction at closing and males reported greater overall satisfaction with transportation and health at closing. This parallels the observation that female participants were typically more isolated at baseline and saw greater benefit and satisfaction improvement with supported integration in this domain. Women, additionally, reported greater continuous transportation barriers (e.g., more medical conditions that complicated public transportation use, less ability to travel to activities at night due to personal safety issues).

With relation to physical health, once again it appears that the data points to a "deterioration averted" interpretation. While there were not statistical differences from baseline through follow-up for the group in general, this means that there was *not* significant deterioration of medical status during, or following, integration activities. Essentially, medical status was maintained across time during integration activities even though deterioration across time is anticipated with populations experiencing disabilities. This speaks to the fact that life quality improvements (especially from satisfaction and mental health standpoints) have a powerful impact on medical treatment diversion of costs. Additionally, it is possible that supported integration actually lead to improved care, such as catching medical issues at early stages for outpatient treatment rather than later hospitalization.

It is very important to note that there were times when resources that would have supported community integration could not be obtained even with the assistance of multiple research staff—even when those in the system believed the resource acquisition was appropriate. If, repeated attempts to obtain eligible resources were unsuccessful, there were funds available in the research budget that were used to obtain the resource.

Are there differences in the success of community integration based on age group?

There clearly are some indications differences exist in the success of community integration across age groups. This was especially evident in the youngest group of participants (ages 1–18). The children reported the least physical functional impairment across time (SF-12 scores) and reportedly had the greatest productivity (CIQ scores). It is important to note that the CIQ Productivity score represents the frequency of participation in schooling, employment, or volunteer work outside the home. Given that children with disabilities are mandated by law to participate in education, productivity scores may represent the impact of public education programs rather than what is typically thought of as "productivity" in society in general.

Also relevant to this study are problems of substance abuse, which although reported to be a minimal problem in this cohort of Effectiveness Study participants, may stand as this nation's number one health problem (Robert Wood Johnson Foundation, 2001). Substance abuse issues have finally begun to reach the radar screens of a number of public and private organizations; but even before now it was imperative that action be taken to increase awareness of, and concern for, this momentous public health problem during community integration efforts with all age groups.

Alcohol is the primary substance of abuse among young people and adults. More than 100,000 deaths each year in the United States are directly attributed to its effects. Drunk-driving accidents, domestic and gang violence, chronic health effects, and binge drinking contribute to illness, disability, and death across the country and across every age group.

Among the elderly, alcohol abuse is a significant public health issue. Population statistics indicate that while alcohol use and misuse tend to decline with age, a large number of elderly Americans consume alcohol on a regular basis, with some developing late-onset alcohol use disorders. Recent estimates from the National Household Survey on Drug Abuse (Substance Abuse and Mental Health Services Administration, 2001) suggest that as many as 21 million elderly individuals consumed alcohol within the past month. Of these, approximately one million were classified as heavy drinkers (i.e., 5+ drinks on one occasion on each of 5+ days within the past month) and five million were classified as binge drinkers (i.e., 5+ drinks on the same occasion on at least one day within the past month). Older men were four times more likely than older women to drink heavily. Given that the elderly constitute the fastest growing sub-population in this country, proportional increases in the number of older drinkers can be expected within the next few years. Furthermore, the next generation of elderly citizens (the "Baby Boomers") includes a greater proportion of alcohol users and abusers compared to the current cohort of seniors (National Institutes of Alcohol Abuse and Alcoholism, 2000).

Are there differences in the success of community integration based on disability group?

Two significant differences in integration outcomes appear across primary disability groups. Individuals with developmental disabilities/mental retardation (DD/MR) report better outcomes in two domains. Individuals with a DD/MR primary disability report significantly less physical impairment than individuals with either mental illness or physical disability/primary disabilities. This is somewhat surprising, given the high level of co-morbidity for medical complications with DD/MR disabilities. One would anticipate that the individual's with mental illness would be the least physically impaired. This finding may represent both the strength of existing DD/MR programs in supporting these individuals and the important role that poor mental health plays (for individuals with mental illness) in the deterioration of physical functioning.

The DD/MR population also reported the highest productivity with the other two disability groups (MI & PD) not being significantly different. It should be noted here that there were no ("older adults") with DD/MR participating in the study. We hypothesize that our difficulties in recruiting for this particular cohort was largely a function of the decreased life expectancy for this group of individuals. Therefore, given the empty cell for older adults experiencing DD/MR, this finding of superior productivity represents only children and adults (18–54). Once again, the bias for educational activities representing high productivity scores is likely to drive this finding for children. Additionally, with the "retired" older adult population not represented, adult individuals of typical employment age and children in the public education system only contributed to this difference. Once again, this difference may represent the strength of educational and supportive employment programs for individuals with DD/MR disabilities. These findings possibly suggest that supportive employment strategies are currently more successful for individuals with DD/MR disabilities than for other disability groups. Further research is needed to clarify this possible interpretation, however.

All three disability groups differ significantly from each other in their experiences of depressive symptoms. As might be anticipated, individuals with mental illness report the highest depression (BDI-II scores) levels, reporting a group "average" of what is categorically a "mild" depression. As a reminder, individuals with mental illness included individuals with diagnoses that may or may not include depressive symptoms, and there was wide variability (extreme highs and low scores) in depression reported by individuals within this group. The group average for individuals with physical disabilities was significantly lower than the group average for individuals with primary mental illness, but individuals with DD/MR disabilities' scores were significantly lower than both groups. In fact, the group average for individuals with DD/MR was lower than general population norms would suggest.

Finally, across disability groups, males with physical disabilities who were in the adult group demonstrated significantly higher levels of depression than all other participants. From a theoretical standpoint, it is reasonable to assume that the psychological impact of social gender roles (i.e., expectations of an adult male to be employed and physically capable) create the setting for differential impact of physical disabilities. The functional impairment associated with physical disabilities is in direct conflict with "success as a male of employment age." Such incongruence between one's "ideal" and the ongoing reality can strongly contribute to depressive symptoms. This would suggest a need for special attention to programs supporting physical disability adaptation and depression coping skills for men. Such interventions may be critical to reducing the depression of adult males with physical disabilities.

Overall, the data from this project strongly support the idea that supporting community integration increases individuals overall well-being. An important secondary gain evidenced in this sample of participants was the significant reduction in the amount of traumatic stress participants were currently struggling with related to past stressful experiences. While trauma symptoms and related difficulties were not directly addressed within the community integration project, traumatic stress was highly impacted by participation in self-directed community integration activities. This suggests that simply improving general quality of life for individuals by fostering greater independence and self-reliance can have a significant impact on other, more serious mental health problems.

Participants within all age groups and disability types demonstrated improvement, or maintained stability, throughout the duration of the project. While there was general improvement and/or stability, there were differential effects related to age and disability type, as would be expected due to the plethora of possible differences. Such differences among these groups help to provide more useful and appropriately specific suggestions for improvements, and understanding of particular needs, based on the individual.

Section References

American Psychological Association. 1994. *Diagnostic and Statistical Manual of Mental Disorders:* 4th Edition. Washington, DC: Author.

National Institutes of Alcohol Abuse and Alcoholism. (2000). *Tenth Special Report to the US Congress on Alcohol and Health.* Washington, DC: US Department of Health and Human Services.

Robert Wood Johnson Foundation (2001, February). *Substance abuse: The nation's number one health problem.* Waltham, MA: Robert Wood Johnson Foundation.

Stamm, B.H., & Rudolph, J.M., Dewane, S., Gaines, N., Gorton, K. Paul, G., McNeil, F. Bowen, G. Ercolano, M. (1996). Psychometric review of Stressful Life Experiences Screening. In B.H. Stamm (Ed.). *Measurement of Stress, Trauma and Adaptation.* Lutherville, MD: Sidran Press.

Stamm B.H., Rudolph M.A., Smith A. & Varra E.M. (1998) Life status review: monitoring biopsychosocial risk factors in traumatic stress. Available at: http://www.isu.edu/~bhstamm/pdf/LSR_pos.pdf

Substance Abuse and Mental Health Services Administration. (2001). Substance use among older adults. *The National Household Survey on Drug Abuse Report* (November 23).

SECTION 9: ECONOMIC & FINANCIAL REPORTS

ECONOMIC REPORT

The United States Supreme Court's 1999 Olmstead v. L.C. decision has begun to accelerate trends in the delivery of healthcare and support services to the elderly and people with disabilities that were already taking place (Vladeck, 2003). In its interpretation of the Americans with Disabilities Act (ADA), the court held that unjustified and undesired institutionalization and isolation of people with disabilities was a form of discrimination and violated ADA tenets. States were directed to provide community-based services to people with disabilities who were entitled to institutional care. Recognizing that state resources are finite, the court held that community placement would need to be reasonably accommodated, taking into account the needs of those requiring state-supported institutional, long-term care services. "Reasonable-modifications" in programs has been interpreted to mean provision of services in a budget neutral manner. The decision does not mandate the expansion of programs or program expenditures. It does, however, require rethinking how long-term care and other services are provided to the elderly and people with disabilities. States were expected to develop and apply plans to accommodate those people eligible for, and desiring, services in the home and community. The concept was to provide cost-effective services that would help elevate the health status, level of independence, and overall quality of life of people with disabilities and/or the elderly (Rosenbaum, 2000).

A key aspect was inculcating independence based on the promotion of self-determination. To successfully achieve this kind of goal on a long-term basis demanded the active involvement and support of those people for whom the plan was intended; people with disabilities had to help make these life-changing decisions based on their own desires, tastes, and preferences. There is both theoretical and empirical evidence that those with higher levels of self-determination experience higher levels of social involvement, quality of life, and even health outcomes (Leff et al. 2003). Systems that foster independence and self-determination are also desirable because they can be designed and operated to offer flexibility in program financing and resource use. Alternative methods of delivering healthcare and support services can be developed and applied in financing systems to allow for the movement of resources among competing needs. This sort of flexibility maximizes the allocation of limited resources at any given period of time and in this instance for services to people with disabilities.

Medicaid, healthcare generally used by the very poor, is the major source of financing of long-term healthcare and support for people with disabilities. This is namely because people with disabilities are characterized as having very low incomes as they are usually so severely affected by disabilities that they cannot work. Nationally about 78% of Medicaid recipients with disabilities are also eligible for Supplemental Security Income (SSI). This provides income only up to 74% of the federal poverty level. Social Security Disability Income (SSDI) payments may be made to disabled adults who are expected to remain disabled for at least a 12-month period and this has worked to augment incomes in the past. Medicaid is thus a very basic support program for people with disabilities (O'Brien & Elias, 2004). Many long-term care services provided by Medicaid are support services that help people function physically and socially.

While Medicaid long-term care services were originally conceived to be largely institutionally based, since 1984, a significant shift in services has occurred. A substantially greater proportion of Medicaid funds are now allocated to Home and Community Based Services (HCBS). Today, about one third of all Medicaid expenditures on long-term care services are devoted to HCBS, either through the general State Medicaid program or HCBS 1915(c) waiver programs. There are important differences in these mechanisms. There is great flexibility under HCBS waivers for the provision of a broad range of services not covered by Medicaid. These may include respite care, homemaker services, assisted living, employment services, and more.

The HCBS waiver programs allow flexibility in a number of ways. Unlike Medicaid mandated services, they can determine benefit structure, eligibility, cost-sharing, and wait-list requirements. Waiver programs must be cost neutral and operate within budgetary constraints. For Medicaid, those people eligible for services must receive the services mandated for the program while HCBS waivers provides a viable avenue for expanding long-term care and support services for people with disabilities and the elderly. They have also proved effective as a cost-containment mechanism. It is important to understand the dual nature of the HCBS waiver mechanism. The waiver process clearly recognizes the high degree of substitutability of institutional and alternative services for the elderly and people with disabilities. It affords the opportunity to provide a broader range of cost-effective services and even extend those services to additional beneficiaries within the constraints of available resources. However, the cost-containment measures can be restrictive. These include enrollment limits, expenditure caps, and cost-sharing, which can result in a reduction of services to participants. This potential grows higher as state budgets are strained during economic downturns in the economy such has occurred over the past few years (Reester, Missmar, & Tumlinson, 2004). Still, HCBS waiver programs clearly illustrate the alternative opportunities to institutional care that can be made available for service provision even though expenditures for institutional long-term care services under Medicaid still account for about two thirds of the total.

Economic Analysis

Our analysis of Idaho's Medicaid services delivered to people with disabilities investigated the degree that available resources could be reallocated to different services for these populations. The major research questions involved the role of choice in elevating client satisfaction, quality of life, and functional and health status for those with disabilities. Providing and weighing alternatives was critical if self-determination at any level was to be gained for people with disabilities.

While the primary goal of the collection and analysis of Medicaid cost data was to (1) determine the costs and benefits of program interventions, this economic analysis also helped to accomplish the following: (2) define the dimensions and economic parameters of the systems serving people with disabilities; (3) provide an analytic framework for estimating aggregate program and community costs, benefits, and intervention-specific cost-effectiveness; (4) provide an ordered method of determining the types and volume of resources-use data that must be collected to document program costs; (5) determine the relative costs of research and intervention activities; and (6) provide a method of assessing intervention-specific costs.

To construct valid statements on the cost-effectiveness of alternative strategies and programs aimed at the optimal independence of broad categories of people with disabilities, it was necessary to carefully measure and document the program's resource expenditures. Once that was complete it was necessary to analyze the degree services and activities could reasonably be substituted for each other. For this report, much of the analysis could only directly address intervention and programmatic costs. In order for cost-effectiveness of alternatives to be determined the results of the Effectiveness Study must be looked at jointly as part of this research. Therefore, this study investigates the economic implications and tolerances of substitution of home- and community-based services for those that have been traditionally and historically provided for in more institutionalized settings. In addition, where feasible, analysis of additional non-health-related services and programs is also added as these services make it possible for people with disabilities to attain and maintain their ability to live as independently as possible in their communities. Employment services, housing, community support, transportation, and educational services are only a few of these enabling services crucial to self-determination and optimum community independence. Providing options and allowing those with disabilities and/or their families to actually make resource- and service-related choices is the key to self-determination.

Substitution of Services

Basic to this discussion of alternative services is the concept of economic or opportunity costs. While there are many cost concepts relevant to measurement of the economic value of services, the most useful is that of opportunity cost. Opportunity cost is the foregone value of current use of an economic resource or asset. It is the highest-valued opportunity foregone to allow current use. Therefore, the opportunity cost for institutional long-term care services may be the foregone use of alternative home- and community-based services. Once a resource is used it is not available for further or alternative use. That use is foregone. This concept helps order resource decisions so that a more optimal use of funds can be made. It may be feasible to provide home- and community-based services to more beneficiaries while increasing the level of beneficiary satisfaction, quality of life, and level of self-determination. There is substantial evidence that this is the case in the provision of long-term care services to the elderly and to people with disabilities.

The concept of opportunity cost is particularly relevant to the services provided for people with disabilities and the elderly because implicit costs are nearly always ignored. The largest component of implicit costs in long-term care is the unpaid care adults receive at home. Approximately 80% of those who get long-term care at home rely on unpaid care. This amounts to huge implicit or opportunity costs that accrue to these services. While difficult to measure and aggregate, these costs must be accounted for in estimating the total cost of long-term care services

The jury has been in for quite a long time on the question of whether alternative, especially home- and community-based, services can be effectively substituted for skilled nursing facility and other institutional services. In fact, medically, socially, and economically there are great opportunities to effectively substitute service categories and settings without lowering the overall health status or functional status of those receiving the services. The feasibility of efficient substitution of non-institutional care for institutional care has been accepted for a long period of time. A classic econometric study of data from 1963–1973, a period that includes the early years of Medicare and Medicaid implementation, calculated a very high price elasticity of demand (-2.3) for nursing home care. Elasticity measures sensitivity of demand to changes in price and price proxies such as insurance coverage. When few effective substitutes for a service exist then elasticity is very low (less than -1). An elasticity of -2.3 is very high and strongly indicates that there were effective substitutes available for nursing home care and that these could be effectively adopted by those using long-term care services(Chiswick, 1976). This is a very strong economic argument for providing alternatives for institutional long-term care. This economic basis for the substitution of institutional care coupled with the desire to attain and maintain independence supported the need for developing successful home- and community-based services. The fact that these services can be provided cost-effectively, reinforced their rapid development and diffusion through Medicaid's HCBS waiver.

Research on the replacement of institutional care offers both broad and deep evidence. For example, another early study looked at the cost-effectiveness of providing services in institutional and alternative long-term care settings. Ten nursing facilities and ten closely matched non-institutional long-term care programs were studied to determine the degree of substitutability of settings and services. The study found that for broad ranges of people with disabilities and for the elderly, alternative settings can provide highly cost-effective services and result in higher quality of life for patients at many different levels of health status (Piland, 1978).

The experience of the HCBS waiver programs, as well as a continuing stream of recent studies, have consistently found that a wide range of long-term care services can be delivered in effective and cost-effective ways to a broad range of the disabled population. However, "cost-effective" does not always imply lowest cost. This is a complex question in the evaluation of program effects for groups of individuals that face many life challenges. The healthcare and social support systems in which they function are exceedingly complex and they often face the constraints of limited financial and human resources. In addition, there is usually a temporal aspect to accrual of cost and benefits of programs and services. Benefit and cost may accrue over time and are difficult to accurately calculate at any one point. For example, a recent evaluation of the Arkansas Medicaid Cash and Counseling program (IndependentChoices) showed that it is difficult to predict both short- and long-term effects of innovative programs. This is an important demonstration program that allows Medicaid beneficiaries to actually direct expenditures for their Personal Care Services (PCS) by allowing participants a monthly allowance from PCS to spend on services. Participants are permitted to make their own spending decisions with the help of representatives that they choose. If they wish, the representative they hire can be a relative rather than those provided by agencies. This is an important experiment in self-determination in a very important arena—providing the participant the ability to spend Medicaid funds for the services they believe most appropriate. Material involvement in spending decisions regarding your own, frequently very intimate, personal care is a central tenet of self-determination. The most significant finding of this demonstration has been that participant needs can be better met at no greater cost. While the per capita monthly cost of personal care services was greater over the period of the demonstration, this excess cost was offset by reduced utilization of other long-term care services. This demonstration program indicates that Independent Choices, a counseling- and consumer-directed care option helped provide access to home-care services that proved to be a cost-effective and viable option to more expensive Medicaid Services, especially nursing home care (Dale et al. 2003). Several states are currently experimenting with similar options to improve consumer direction in their Medicaid programs.

Research on long-term care services and the experience of HCBS provided under 1915(c) HCBS Medicaid waivers each indicate that participant satisfaction can be elevated along with quality of life when participants are provided with carefully designed and operated home- and community-based service programs. The higher the degree of consumer participation and self-direction the more likely the program will be successful in providing acceptable services that help beneficiaries attain and maintain the highest level of independence. It is clear that a broad range of long-term care services can be effectively substituted for each other. Determining the proper mix of services for each beneficiary is exceptionally important in maximizing Medicaid's available resources. The level of participant involvement in accomplishing the right mix is equally important.

Real Choices for People with Disabilities in Idaho

Economic analysis helps order alternatives and makes the consequences of resource-related choices more explicit. Opportunity as well as explicit costs can be identified and quantified. As such, it is a highly useful tool in helping provide guidance for the provision of cost-effective services. However, cost-effectiveness is only one portion of the total picture of service provision under Medicaid. Therefore, this assessment only addresses the dimensions and possibilities available for the expansion of non-institutionally based services within the constraints of currently available resources. The analysis describes patterns of expenditures for long-term care in Medicaid and identifies economic and policy options for the expansion of alternative (mainly home- and community-based) services in Idaho. Real Choices initially identified a list of problems that effect the allocation and reallocation of Medicaid resources to various segments of the long-term care system. Potentially, these may cause delays in the implementation of policies designed to shift resources to home- and community-based services. Some of the problems include (1) the disparate spread of Idaho's disabled population across urban, rural, frontier, and tribal communities; (2) the state is affected by a serious shortage of health services and healthcare providers; and finally (3) the infrastructure for community-based services is immature and still developing. The implications for these problems are complex and serious. The healthcare delivery system is not completely segmented into systems that care for specific portions of the population. Therefore, the health status, healthcare use, and cost of care provided to any one population effects the entire system of financing and delivery of health services. Over 65% of the state's population resides in primary care Health Professional Shortage Areas (HPSAs) as designated by the Health Resources and Services Administration (HRSA). In 2003, all but two of Idaho's 44 counties were designated as Mental Health Personnel Shortage (MHPSs) areas. In addition, HRSA describes severe current and projected shortages in nursing personnel. Nursing services are key components of both acute and long-term care services. Such shortages put additional strain on a system already experiencing difficulty in meeting the demand for all levels of healthcare services. Because of developing community-based services, although substantial progress has been made in Idaho through HCBS waivers, people with disabilities can still be isolated in institutions or private personal care settings that prevent integration into their communities (HCBS, 2003). Real Choices is investigating each of these problems through its Needs and Resources Study, Effectiveness Study, and this Economic Assessment.

Study Data

Data for the study was gathered from a number of sources. Idaho Medicaid was acquired from the Idaho Division of Medicaid within the Idaho Department of Health and Welfare (IDHW), which is grantee for Real Choices. Data was also gathered from the Centers for Medicare and Medicaid Services (CMS) website (http://www.cms.hhs.gov/). This source is a repository of statewide data submitted by Medicaid programs in all states and territories. It hosts comprehensive and complex datasets available for download and analysis. CMS data also was used in a state-by-state Medicaid analysis. Additional data was provided by the Kaiser Family Foundation's Kaiser Commission on Medicaid and the Uninsured, the CMS Division of Disabled and Elderly Health Programs, and the Supported Living Project of the

Idaho Council on Developmental Disabilities. Data was also acquired from the Medicaid HCBS waiver Expenditures Reports collected by Medstat Inc. from CMS Reporting Form 64. This report is required for HCBS waiver programs approved by CMS. Smaller quantities of data from several other sources were also integrated into the study (Eiken, Burwell, & Schaefer, 2004). Some estimates of expenditure and utilization were synthesized from other data sources. Therefore, slightly different timeframes for reporting and reconciliation resulted in some estimates that vary slightly from reported data. For example, data reported for the Idaho state Fiscal Year and the Federal Fiscal Year (aggregated for CMS reporting) report minor differences. When possible these differences were reconciled. The estimates are intended to be used as ranges within which predicted expenditure and utilization can be calculated.

Patterns of Medicaid Expenditures for Long-Term Care in Idaho

Idaho was a relatively early adopter of the HCBS waiver process as a means of controlling Medicaid costs and leveraging Federal matching funds to reduce control of the rise in State spending. Moving patients from State-funded facilities such as Idaho state hospitals and schools to community facilities means that Medicaid's Federal match pays for a large part of the care that was previously paid entirely from State funds. In 2004, the Federal Medical Assistance Percentage (FMAP) for Idaho was 73.9%. This includes a 2.95% temporary increase from a Congressional appropriation aimed at State fiscal relief. The FMAP will be 70% in 2005. Leveraging the FMAP though HCBS waivers has had at least two major effects: (1) HCBS expanded greatly in a brief period; and (2) spending on long-term care grew faster for HCBS services than for institutional care over the past five years.

Table 9-1 details the growth in Medicaid expenditures from FY 1998 to FY 2003, the latest year for which complete data is available. While growth in total expenditure for Medicaid was relatively stable over the last few years, following the state's population growth and recent economic downturn, changes in the distribution of Medicaid expenditures for long-term care was dramatic. In addition, the Kaiser Family Foundation, in a recent analysis, reported that in 2002, Idaho's Medicaid program spent about 75% of its funds on elder, blind, and disabled care while these populations accounted for only 24% of the beneficiary population (Kiplinger, 2004). The relatively high per capita cost for elder and disabled care

Table 9-1. Growth of Medicaid Expenditures in Idaho FY1998–2005

Total Medicaid		Hospital Inpatient	Nursing Home	Total Long-Term Care	Total HCBS
1998	$448,884,170	84,624,091	92,882,553	175,562,309	16,181,274
1999	517,507,218	82,451,660	108,636,325	198,195,055	17,271,449
2000	586,028,499	84,631,687	111,736,671	222,800,311	33,698,431
2001	706,213,899	100,093,452	118,971,162	257,930,140	58,516,092
2002	798,906,740	125,594,321	122,176,246	277,166,785	76,576,159
2003	837,686,711	124,807,708	125,295,015	306,138,938	88,655,862

Source: CMS 64 data, Center for Medicaid and State Operations, Division of Medicaid provided an immediate and sustained incentive for cost-containment. As the population ages this becomes more urgent.

Table 9-2 illustrates the rapid growth in HCBS waiver expenditures. These services proved good alternatives to traditional institutional services. Their rapid growth indicates that they are close substitutes for institutional care and can provide services at a lower unit cost to a large range of the disabled and the elder population.

Table 9-2. Avg Compound Rate of Growth in Medicaid Expenditures by Type of Service FY1998–2003

Total Medicaid	13.4%
Hospital Inpatient	8.6%
Nursing Home	6.34%
Total Long-Term Care	10.8%
Total HCBS Waivers	40.5%
Source: CMS 64 data, Center for Medicaid and State Operations, Division of Financial Management	

Table 9-3 details the distribution of Medicaid funds. In FY 2003, HCBS accounted for 10.6% of total expenditures while long-term care consumed 36.5%. Total home-based care and nursing home care accounted for a greater proportion of total expenditures than inpatient hospital care. This proportion differs markedly from general national health expenditures. In 2002, inpatient hospital care accounted for about 36% of total expenditures. The difference is due to the special needs of the populations Medicaid serves and the nature of the provided care.

Table 9-3. Distribution of Medicaid Expenditures by Service, Idaho FY2003 (millions)

Program/Service	Expenditure	Percent of Total
Total Medicaid	$837,686,711	100%
Inpatient Hospital	124,807,708	14.9%
Drugs	132,143,091	15.8%
Long-Term Care	306,138,938	36.5%
Nursing Home	125,295,015	15.0%
ICF-MR	54,266,274	6.5%
Personal Care	31,472,503	3.8%
Total Home Care	126,577,649	15.1%
HCBS MR/DD	36,698,083	4.4%
HCBS A/D	50,782,660	6.0%
Brain Injury	1,175,119	.001%
Total HCBS Waivers	**88,655,862**	**10.6%**
Source: CMS 64 data, Center for Medicaid and State Operations, Division of Financial Management		

The growth of home-based services is illustrated in Table 9-4. From 1998–2003, home-care services grew from 20.4% of the total expenditures for long-term care to 41.3%. This represents a significant change in the proportion of long-term care provided in institutional and alternative settings. This trend is also shown in Table 12-5. As a proportion of Medicaid spending, institutional long-term care service spending fell from 34.7% of the total in 1998 to 23.7% in 2003.

Table 9-4. Growth of Home-Care Expenditures, Idaho FY1998–2003 (millions)

Medicaid		Nursing Home	Total Long-Term Care	Total Home Care	Home Care % of Total Long-Term Care
1998	$448,884,170	92,882,553	175,565,309	35,886,759	20.4%
1999	$517,507,218	108,636,325	198,195,055	40,630,717	20.5%
2000	$586,028,499	111,736,671	222,800,311	57,853,111	26.0%
2001	$706,213,899	118,971,162	257,930,140	77,947,434	30.2%
2002	$798,906,740	122,176,246	277,166,785	99,739,643	36.0%
2003	$837,686,711	125,295,015	306,138,938	126,577,649	41.3%

Table 9-5. Change in Institutional & Home- & Community-Based Long-Term Care Percent of Total Medicaid Expenditures, Idaho FY1998–2003

Year	Institutional Care	% of Medicaid	Home Care	% of Medicaid
1998	$155,940,182	34.7	$35,886,759	7.9
1999	174,650,329	33.4	40,630,717	7.9
2000	183,920,674	31.4	57,853,111	9.9
2001	205,662,585	29.1.	77,947,434	11.0
2002	197,772,578	24.8	99,739,643	12.5
2003	198,391,715	23.7	126,577,649	15.1

Over the same period, home-based care rose from 7.9% to 15% of total expenditure. There has been a clear and sustained shift of long-term care services from institutional to home and community settings. HCBS waiver programs have proved to be an exceptionally flexible and effective vehicle in facilitating this rapid change in long-term care patterns.

Table 9-6 shows the distribution of expenditures across Idaho's four HCBS waiver programs from 1998 through 2003. It also shows the annual compound rate of growth in spending for each of the programs, in which each exhibited significant growth. The two largest programs, A&D and Developmental Disabilities/DD/MR accounted for over 95% of the total waiver program expenditures in 2003.

Clearly there has been a significant shift in Idaho's patterns of long-term care services. Alternative services, largely home- and community-based services provided under Medicaid 1915(c) waivers, have become the avenue for change from an institutionally based system to one characterized by an increasing range of services provided in home and community settings. This was achieved through the delivery of highly cost-effective services. Table 9-7 illustrates the comparative costs of each of Idaho's HCBS waiver programs and institutional care in nursing or intermediate care facilities.

Table 9-6. Growth of HCBS-Waiver Expenditures, Idaho FY1998–2003

Year	A/D	MR/DD	ISSH	BI	Total
1998	$6,311,332	$9,171,207	$698,735	N.A.	$16,181,274
1999	6,598,394	9,574,035	1,099,020	**N.A.**	17,271,449
2000	15,120,499	16,658,226	1,637,296	282,410	33,698,431
2001	29,751,560	26,028,606	2,198,252	546,674	58,516,092
2002	45,107,403	28,114,098	2,603,802	741,856	76,567,159
2003	50,782,660	33,536,087	3,161,996	1,175,119	88,655,862
ACRG* 1998-2003	51.7%	29.6%	35.2%	60.8%	40.5%

*Annual Compound Rate of Growth

Table 9-7. Cost Comparisons for SFY2001–2002 Total HCBS Waiver Programs & Institutional Care

Waiver Type	A&D	TBI	MR/DD	ISSH
Avg. Enrollment Per mon. SFY' 02	3647	9	1028	57
Cost Comparison	Nursing Fac.	Nursing Fac.	ICF/MR	ISSH Inpat.
Institutional Cost	$133/day $4,049/mo.	$226/day $6,888/mo.	$2112/day $6,448/mo.	$278/day $8,456/mo
Total Average Cost/ Waiver Services	$23,502	$46,355	$45,501	$84,208
Total Average Cost/Institutional Services	$41,445	$128,842	$64,473	$155,839
Waiver Cost as a % of Institutional Cost	57%	36%	71%	54%

Source: Research and Statistics Unit, Division of Medicaid, Idaho Department of Health and Welfare, 2003.

As required by the Federal waiver requirements, all of Idaho's HCBS waiver programs proved to be cost neutral. In addition they appear to be highly cost saving. HCBS costs, in comparison with traditional institutional costs, range from 29% lower for MR/DD to 64% lower for Traumatic Brain Injury (TBI). The largest program, A&D, showed 43% lower costs. These are significant differences and indicate that further expansion of home- and community-based services is possible within the constraints of currently available resources.

HCBS deliver at lower costs. However the key to further expansion is the question of cost-effectiveness. Accurate estimates of cost-effectiveness depend on good measures. Home- and community-based services can be substituted for institutional care for a large proportion of people with disabilities. The Effectiveness Study phase of Real Choices with quality data can ensure further expansion. Testing and evaluation procedures adopted for the study are designed to facilitate accurate and effective placement of participants. They are also intended to provide information for the generation of predictive techniques that can be used to correctly identify patients most likely to benefit from HCBS. While cost cannot be the most important factor in determining the receipt of alternative or institutional services, it certainly is an important factor and must be carefully entered into any equation aimed at estimating the type of care most appropriate for people with disabilities. An exceptionally important factor is that of self-determination. This is important for participant satisfaction, quality of life, and health status since it is demonstrated that those program participants most actively involved in the planning and involvement of their own care have better quality of life and health outcomes. These are good measures of effectiveness and provide the information necessary to calculate the cost-effectiveness of each program and its individual elements.

Program savings for Medicaid can be quite dramatic. For example, a recent survey reported by CMS of Idaho's nursing home residents found that 25% (1143) of the 4750 nursing home residents indicated a preference for returning to the community. Assuming that this preference is medically appropriate and achievable through the HCBS A&D waiver process, the savings are substantial. Using the 2002 data reported above, HCBS placement would result in a savings of at least $20.5 million. The real savings would probably be substantially higher because the current nursing home cost in Idaho is higher. The GE Financial Survey of homes found that the 2003 average annual cost of nursing home care was $54,000 (Kiplinger, 2004).

This analysis indicates that a substantial opportunity remains to provide HCBS to a larger proportion of the disabled population on Medicaid. These services have the potential of providing care that is both cost-effective and capable of meeting the goals of self-determination and consumer-directed services.

As noted above, this analysis is intended to help guide the allocation of resources across a spectrum of possible demands. This has not and will not be a simple task because of the many alternatives that may be adopted that are capable of attaining a given or planned level of independence. The multiple categories and definitions of disabilities and the many levels of cognitive and functional abilities within each category make the precise allocation of funds to competing programs and preferences exceedingly difficult. However, it is clear from the analysis that great improvement in levels of beneficiary satisfaction can be achieved through analytic mapping of funding resources presently available in the Medicaid program with the preferences of beneficiaries with disabilities.

Summary and Conclusions

Analysis infers that multiple methods and formulae for each category and level of disability will be more productive and cost-effective than attempting to derive a single capitation rate for clients within broad categories. Rather, actuarially determined capitation rates calculated for discrete severity levels for carefully defined and assessed clients within the broader categories is indicated. The Effectiveness Study is designed to inform this process through careful matching of thoroughly evaluated and assessed clients that represent both existing categories of disability and levels of severity within categories. This is an intense and resource intensive process. These assessment costs also need to be calculated and included in each capitation rate. There is a pressing need for flexibility in the allocation of funds in order to maximize their effectiveness in attaining the goals of each client and program.

The analysis also indicates that their may be problems in optimizing the use of available resources from both the demand and the supply sides of the equation. On the demand side individuals with disabilities and the resources required to attain and maintain maximum independence and quality of life are not readily aggregated to facilitate movement across different types and levels of care and support. On the supply side, it is clear that not all and perhaps relatively few communities have the required mix of providers and services to meet the demand of the beneficiary population. In addition, services are not currently organized to provide either flexibility or evaluation of effectiveness. This initiative requires broad range health, transportation, and social services along with the encouragement of individuals to "self-determine" their use of the services. This must all be accomplished from among the available resources. Therefore, many choices must be made in both the provision of services and their utilization. The Economic Analysis and Effectiveness Studies provide critical information on the demand and supply of services, optimization of client satisfaction, and the use of available resources from Medicaid and other sources.

Significant Findings

- There was substantial activity and progress on the part of Idaho's disabled populations to develop alternatives to institutional long-term care well before the Olmstead Decision (Olmstead v. LC, 1999). The decision did have the effect of accelerating changes in the long-term care system and providing greater empowerment for people with disabilities and their advocates.

- Olmstead and the subsequent CMS-funded Real Choices System Change grant series did not provide new funding for the expansion of alternative community-based services. The Olmstead ruling specifically charged Medicaid with providing alternative services within budgetary constraints. However, resources for planning and demonstrating the feasibility of making significant changes in the system have been made available and are facilitating the planning and implementation of services and programs designed to help enable people with disabilities to actively participate in the selection of their services and systems of support.

- For all categories of Medicaid services, Idaho spent slightly more per capita than the average of all states: $3,877 vs. $3,762 (2002).

- Long-term care services consume 36.5% of Idaho's Medicaid budget.

- Idaho Medicaid is the primary source of services for low-income elderly and disabled citizens. Fifty (50) % of all Medicaid spending went for the care of the blind and disabled in 2000. An additional 25% was spent for care of the elderly. So, 75% of Idaho's Medicaid expenditures were for care of the elderly and disabled.

- Idaho Medicaid acknowledges that skilled nursing facility costs have moderated in the last few years largely due to the expansion of the HCBS waiver programs. This indicates that the opportunity for further substitution of HCBS for institutional long-term care may be increasingly attractive. It may also offer the opportunity of either expanding the range of services offered in the community or the number of recipients within the constraints of current budgets.

- Idaho's HCBS waiver program has grown significantly and is an increasingly important component of Medicaid's programs. From 1997 through 2002 the HCBS waiver program expenditures grew substantially as a proportion of total Medicaid and total Medicaid long-term care expenditures: 10% of long-term care and 4% of total Medicaid in 1997 to 28.9% of long-term care and 10.6% of total Medicaid in 2003. This is an extremely significant trend.

- While it is certainly true that a large proportion of the Medicaid recipients receiving institutional care (skilled nursing facility, intermediate care facilities/ [ICF/MR], ICF/ISSH, Nursing Facility/SHS) are appropriately placed, it is also true that HCBS services can be provided less expensively and the opportunities for further expansion of these services are feasible.
- However, per capita costs for recipients of long-term care services are substantially higher for institutional care even though the required level of care for most recipients may demand higher costs. Based upon the historical expansion of these programs, it is very likely, though, that a considerable proportion of Medicaid recipients of long-term care services can benefit from HCBS at a substantially lower cost than is being realized.
- There appears to be substantial remaining opportunity for the provision of cost-effective long-term care services through HCBS programs that meet the goals of both cost-containment and client self-determination for Idaho Medicaid and Idaho's population affected by disability.

Section References

Chiswick, B. (1976). Demand for nursing home care: An analysis of the substitution between institutional and non-institutional care. *Journal of Human Resources, 11*(3): 295-316.

Dale, S., R. Brown, B. Phillips et al. (2003). The effects of cash and counseling on personal care services and Medicaid costs in Arkansas. *Health Affairs*, W3-566, November 19.

Eiken, S, Burwell, B. & Schaefer, M. (2004). Medicaid HCBS waiver expenditures, FY 1998 through FY 2003. *Medstat*, May 20.

Home and Community Based Services: From Institutional Care to Self-Directed Supports and Services. (2003, May). Center for Medicaid and State Operations, Center for Medicare and Medicaid Services. Washington, DC.

Kiplinger Retirement Report, March 2004.

Leff, S., Conley, J., Campbell-Orde T., & V. Bradley. (2003). Getting to systems that promote self-determination through research & evaluation. National Self Determination & Psychiatric Disability Invitational Conference, Chicago, Il, Oct.

O'Brien, E., & Elias, R.. (2004). Medicaid and long-term care. Kaiser Commission on Medicaid and the Uninsured, Kaiser Family Foundation.

Piland, N. (1978). Cost-Effectiveness and Feasibility of Alternative Long-Term Care Settings, Stanford Research Institute, May.

Reester, H, Missmar, R, & Tumlinson, A. (2004). Recent Growth in Medicaid Home and Community-Based Service waivers, Kaiser Commission on Medicaid and the Uninsured, Kaiser Family Foundation, April.

Rosenbaum, S. (2000). The Olmstead Decision: Implications for State Health Policy. *Health Affairs*, 19(5):228-232.

Vladeck, B, (2003). Where the Action Really Is: Medicaid and the Disabled. *Health Affairs*, 22(1): 90-100.

FINANCIAL REPORT

In this section, we review the expenditures associated with the Idaho Real Choices Effectiveness Study. The Effectiveness Study was conducted between August 2003 and February 2006. In addition to the funds and staffing available through the study, participants received help in accessing their available resources through third-party payers such as Medicaid, Medicare, and private insurance.

The results of the financial analysis showed that a relatively small investment can make a big difference in a person's quality of life. Study participants increased their quality of life and health, maintained their community integration, and avoided long-term care costs. While the results of the financial analysis are promising, two things must be kept in mind. First, even though the amount of time each participant was enrolled in the study was substantial (Mean 13 months, SD X 7.6), the actual number of participants was small. Second, we were unable to track the actual costs of services provided by third-party payers such as Medicaid or private insurance. Given these limitations, while the data describe concisely the participant's community integration costs, it is difficult to extrapolate actual costs for future community integration plans.

Methodology

This study involved 23 participants and their families. Participants were all ages and covered a wide range of disabilities. The overall study lasted 27 months and individual participants were enrolled between one and 27 months with an average of 13 months (SD 7.6). As will be shown below, a relatively small incremental cost over the existing services and support allowed participants to maintain their life in the community and reduce the risks of having to use more expensive institutional or long-term care options.

The analysis is a program cost analysis in that we examine both the fiscal costs and the participant's perceptions of their wellbeing and quality of life following the implementation of their community integration plan. It is difficult to assign a cost to improved quality of life; however, ample literature is available to link reduced stress with better health. Better health should be associated with avoided costs such as reduced utilization of more expensive healthcare services such as hospitalization and long-term care (see Economic Report [pp.95-106], see also Leff, Conley, Campbell-Orde & Bradley, 2003).

Fiscal Methodology

The cost data came from the financial records maintained for the grant, which were maintained in records separate from the general funds of the University. There were two types of costs for which to account; (a) goods and services, and (b) project staff costs.

The assignment of *goods and services* were identified by actual cost for each individual participant.

Staff costs, incurred for implementing the Effectiveness Study, were assigned uniformly across the participants based on mean staff time and degree of difficulty in implementing and/or fulfilling the community integration plan. This standardized method was selected to reduce the idiopathic effect of any single case on the group data. The staffing costs included assessment and evaluation; administrative time; and travel from Pocatello to participants were located 30 to 80 miles away.

Assignment of Assessment Costs. **There were potentially two types of assessments. Each participant completed a full functional assessment at enrollment**

into, and exit from, the study. When appropriate, specialty assessments were completed. For example, specialty assessments might have included audiology exams, specialty mental health evaluations, vocational evaluations, school evaluations, and/or supported employment evaluations. Costs for the functional assessment were set at market rate. Specialty assessments, if used, were also assigned at the market rate.

Staffing Cost Allocation: Difficulty Factor. **Cases were rated for difficulty based on the time spent on the case. A one to four scale was used with one being the least difficult case and four being the most difficult (time consuming).** Weighting were computed based on records reviewed by the clinical and financial staff_as a weighted ratio of the participant's visits to the total visits.

Quality of Life Methodology

The Beck Depression Inventory (BDI), SF-12, and Life Status Review (LSR) were used to assess a participant's mental and physical function as well as quality of life. These measures are fully described in the Effectiveness Study Section (pp. 69-93). Data were collected at a participant's enrollment and exit from the study, as well as on a monthly basis. Data from the LSR is divided into ten life areas: (1) medical, (2) health, (3) financial, (4) housing, (5) transportation, (6) employment/schooling, (7) substance abuse, (8) legal, (9) relations, and (10) leisure.

Results & Discussion

There are two approaches that can be used to calculate per capita costs; therefore the data here are presented in two ways. First, we describe the total study as the unit of analysis, a **program per capita cost**, which is most closely aligned with the costs of running a program. For the second method, we describe the data with the participant as the unit of analysis, **individual per capita costs**, which takes into account the fact that the participants in this study were very different from one another; they came from all age groups with a wide range of disabilities.

Each participant has a unique set of costs. A per capita figure based on the average of the individual average costs is more closely tied to the costs that could be associated with any one individual. This method is the mean of participant means. To obtain the mean of the means, each participant's total costs was divided by the months that participant was enrolled in the program. The individual participant means were summed and divided by the number of participants, yielding an individual participant per capita cost estimate. This method, which takes into account the number of months each person was enrolled in the program, is the basis of the per capita costs reported below.

Program Per Capita Cost

This methodology provides data to estimate total program costs. When using per capita cost we divide the total costs by total enrollee-months. Taking the Effectiveness Study as the unit of analysis, the total project cost was $252,463. Of that, $206,690 was spent on the enrolled participants and $45,773 was spent supporting the participant's family members. Purchased goods and services were $74,894 and staffing $131,796. Using this method, the average monthly cost was $689 per person. The benefit here is that the average is not as strongly affected by any one individual case. This method is perhaps more likely to yield a method of calculating total program costs based on number of enrollees. A calculation of the average assumes that all of the participants are the same and will have the same costs each month.

Below is the category breakdown of the expenditures for the participants. Approximately 64 percent of the costs for the study were staff time with 36 percent of the costs for goods and services. Note that the largest cost category was in staffing.

Table 9.8. Category by Type, Total Program Costs

Cost Category	Participant (a)	Family (b)	Total
Medical-Related Costs	$ 11,238	$ 4,570	$ 15,808
Health-Related Costs	5,077	4,948	10,025
Housing Assistance	21,295	0[1]	21,295
Transportation	4,265	1,007	5,272
Employment/Schooling	4,889	931	5,820
Adaptive Equipment	28,130	1,241	29,371
Staffing Costs	131,796	33,076	$164,872
Grand Total:	**$ 206,690**	**$ 45,773**	**$252,463**

Three classes of staffing time were identified, evaluation, support, and travel. The data reported here includes time spent with the participant, and when applicable, the participant's family. Evaluation costs include functional and appropriate specialty assessments as well as research data collection costs. It was not feasible to separate these assessment costs as the functional and specialty assessment information used to create a participant's CI plan was often also used for research purposes. In some cases, but within the bounds of participant informed consent, research data was collected that was not used in support of the CI plan.

Ongoing participant support from research assistants deserves particular attention. The majority of this time was spent accessing services and supports for which the participant was eligible through their third-party payment system. Many services and supports were quite difficult to access and in some cases it was less expensive to purchase the service or support than to continue to pay for the staff time to access the eligible benefit. In most cases, the programmatic barriers seemed to be relics of a system originally designed to support institutional care as it transitioned toward HCBS.

Staff travel costs were associated with travel to and from meetings with study participants. Costs associated with transportation for study participants were included in the transportation category of study participant costs.

Table 9.9. Staffing Costs by Class

Evaluations	$ 96,250
Ongoing Participant Support from the Research Assistants	59,598
Staff Travel Costs	9,024
Total	**$164,872**

Participant Per Capita Cost

Using the mean of each participant's mean, the average monthly cost per participant was $740. As noted above, this method is based on the individual participant as the unit of analysis. Each participant's total costs were divided by their months in the program. These means were summed and divided by the total number of participants in the study.

---

[1] Housing assistance costs, even if it benefited a family, were assigned to the study participant.

In order to examine more fully the individual differences of participants, several types of comparisons were made across the costs of the plans. There were no statistical differences in costs across the categorical groups of disability, age, gender, staff time, and insurance status.

No statistically significant difference occurred between the three groups ($F_{2,20}$=1.76; p=.20). The per capita costs for people with developmental disabilities was $653 (SD = 218); mental illness was $657 (SD = 250), and physically disabled was $871 (SD = 306). The per capita costs for children (under 18) was $835 (SD = 269.1); for adults 18–54 was $559 (SD = 157.4), and for older adults age 55 and higher $838 (SD = 312.2). While the actual dollar costs are different, there was no statistically significant difference among the three groups ($F_{2,20}$=3.11; p=.07). As with the comparison across disability, this result may be an artifact of the small sample size, or it may in fact mean that on average, there is not a difference in costs based on age.

Potential Cost Savings Associated with HCBS as Compared to Institutional Care

We made the assumption that participant costs for implementing their community integration plans were incurred over and above the costs associated with Idaho's 1915 C Medicaid Waivers. The logic of using the HCBS with a CI plan was to reduce the probability of participants needing to use long-term care alternatives. The types of Waivers in Idaho do not necessarily match the categories of the study. For example, Idaho does not have a separate Waiver for persons with a mental illness. However, the average monthly waiver costs of Idaho's existing waiver's costs can serve as a starting point. Table 9.10 shows the average monthly costs for claims paid by Idaho Medicaid's four Waivers for the period corresponding to the Real Choices study (August, 2003 to February, 2006).

Table 9.10. Average Monthly Costs for Idaho Medicaid's Waivers Claims Paid Out

Type of Waiver	Average Monthly Cost	Average Monthly Waiver Cost/ Average Monthly Participants
A&D Waiver	$ 919	$ 4,452,223/ 4,843
ISSH Waiver	$ 3,836	$ 49,869/ 13
DD Waiver	$ 2,622	$ 4,032,412/ 1,538
TBI Waiver	$ 6,252	$ 87,526/ 14

Source: Idaho Department of Health and Welfare's Monthly Waiver Report, June 2006

The greatest costs savings possible in the current system are avoiding long-term institutional care by increasing HCBS (see Economic Analysis [p. 96]). On average, participants referenced in the Effectiveness Study (ES) had a significant amount of functional impairment (see ES clinical data). Thus, we could expect a reasonably high probability of their utilization of institutional care. During the period of their enrollment in the study, no participant was institutionalized. While it is impossible to calculate the literal

Table 9.11. Cost Comparisons by Type of Care

Type of Care	HCBS + Community Integration Costs	Institutional Care (A & D, ISSH, DD, and TBI, 2002)
Avg mean monthly cost	$2035	$6470

Source: Research and Statistics Unit, Division of Medicaid, Idaho Department of Health and Welfare, 2003.

costs of care not provided due to successfully eliminating the need for the care, it is possible to obtain an estimate of avoided costs. The simplest method is to compare the HCBS costs of a waiver plus the CI services and compare that to the average per capita cost of institutional care (Table 9.11). Because the Idaho Waiver data are based on the program as the unit of analysis, we compared to the program per capita costs.

Quality of Life

The benefit of expending the HCBS and Community Integration can be seen in the improved quality of life of the participants. A statistically significant functional improvement was observed in reduced depression, improved mental health status, health (wellness), and financial status. Detailed information about these improvements can be found in the Effectiveness Study, Section 8 (pp. 69-93), of this document.

SECTION 10: APPENDIX

APPENDIX A: FEDERAL GRANT INFORMATION

Real Choices System Change Grant (Idaho Real Choices Phase I) Grant Information

Name of Grantee	Idaho Department of Health and Welfare, Division of Family and Community Services
Title of Grant	Idaho Real Choices System Change Grant
Type of Grant	Choices System Change
Amount of Grant	$1,102,149
Year Original Funding Received	2001

Contact Information

Ken Deibert, Director
450 West State Street
PO Box 83720
Boise, ID 83720-0036

Cameron Gilliland (Contract Monitor)
450 West State Street
PO Box 83720
Boise, ID 83720-0036
(208) 334-5536

Beth Hudnall Stamm, PhD, Project Director
Institute of Rural Health
Idaho State University
921 So. 8th Avenue, Stop 8174
Pocatello, ID 83209bhstamm@isu.edu

Subcontractor(s)

Idaho State University Institute of Rural Health

Target Population(s)

People of all ages with physical, mental, developmental, or aging-related disabilities and long-term care needs.

Goals

1. Increase ACCESS in all forms
2. Increase AVAILABILITY and ADEQUACY of services
3. Increase or maintain VALUE of services across the system
4. Increase or maintain QUALITY of services across the system

Activities

1. Statewide anti-stigma campaign
2. Needs and resources assessment
3. Economic analysis of current service utilization
4. Community development project
5. Effectiveness study to test and refine a community-based plan

Abstract Idaho Real Choices Project Phase I (2001–2005)

The goal of this project is to create enduring systems change in community long-term services and supports. The plan for change is in two phases: (Phase 1) a statewide anti-stigma campaign and a needs and resources assessment, culminating in a plan for change; and (Phase 2) an effectiveness study to test and refine the plan. There are four objectives: (1) increase ACCESS in all forms, (2) increase AVAILABILITY and ADEQUACY of services, (3) increase (or maintain) VALUE of services across the system, and (4) increase (or maintain) QUALITY of services across the system.

The objectives will be met by an Anti-Stigma Campaign that will pave the way for more successful community integration. A Statewide Assessment of Needs and Resources will establish a baseline of needs and resources. An Economic Analysis of the current system, including Medicaid, will seek to maximize appropriate funding strategies and leveraging of available funds. A Community Development Project to examine the political and fiscal feasibility of addressing access to resources for living will approach this as a community development problem, not a healthcare problem, and an Effectiveness Study will determine the quality and value of the derived plan. The final product will be a plan for statewide implementation that has more integration of services, consumer and stakeholder input, and a monitoring system for continuous quality improvement.

Money Follows the Person (Idaho Real Choices Phase II) Grant Information

Name of Grantee	Idaho Department of Health and Welfare, Division of Family and Community Services
Title of Grant	Idaho Money Follows the Person Project
Type of Grant	Money follows the Person Initiative
Amount of Grant	$749,999
Year Original Funding Received	2003

Contact Information

Ken Deibert, Director
450 West State Street
PO Box 83720
Boise, ID 83720-0036

Cameron Gilliland (Contract Monitor)
450 West State Street
PO Box 83720
Boise, ID 83720-0036
(208) 334-5536

Beth Hudnall Stamm, PhD, Project Director
Institute of Rural Health
Idaho State University
921 So. 8th Avenue, Stop 8174
Pocatello, ID 83209bhstamm@isu.edu

Subcontractor(s)

Idaho State University Institute of Rural Health

Target Population(s)

People of all ages with physical, mental, developmental, or aging-related disabilities and long-term care needs.

Goals

1. Conduct an anti-stigma campaign
2. Conduct a statewide service utilization and economic analysis
3. Conduct a community development project
4. Conduct an effectiveness study

Activities

1. Continue implementation of existing anti-stigma campaign
2. Recruit selected communities to identify and develop supportive resources.
3. Conduct an extended community-based study of the effectiveness of an intensive anti-stigma campaign.
4. Conduct an intensive economic and policy analysis of statewide service utilization since 1995.

Abstract Idaho Real Choices Project Phase I (2003–2006)

Idaho has a comprehensive state Medicaid Plan administered by the Department of Health and Welfare, the umbrella agency for health, welfare, and human services in the state. People with disabilities are entitled to an array of mandatory and optional services under this plan. In 1995, the Department initiated the Community Supports project designed to provide Medicaid-eligible people with developmental disabilities and their families/guardians with increased choice of community-based services and supports and there are similar programs for other types of disabilities and long-term illnesses.

This project will complete a research-validated plan for community integration in Idaho, finishing work begun under the 2001 Idaho Real Choices grant. The project will (1) continue the Anti-Stigma Campaign designed to reduce stigma and facilitate community integration, (2) continue the Economic Analysis of the current Medicaid system to identify ways to reapportion and maximize funding, (3) expand the Community Development Project efforts to examine the political and fiscal feasibility of increasing resources for living from a community development perspective and to create a more hospitable community for people who wish to live in it, and (4) expand the existing Effectiveness Study, to test what best assists people of all ages with any disabilities in reaching their community integration goals.

The project will have significant consumer involvement. The Community Integration Committee, which will oversee the project, is made up of people with disabilities, family members, and representatives of private organizations and public agencies. Community to Community Coalitions will also be established in the research sites to involve a broad base of community members.

This project will produce sustained change through identifying implementation strategies for cost-effective community-based care, a policy that has the State Legislature's support. The project will demonstrate the feasibility of providing such services in a cost-neutral manner to the maximum number of individuals with disabilities in the most integrated settings based on their wants and needs. Products of the work will include a research-based community integration plan, evidence-based protocols for Anti-Stigma Campaigns, Community Development projects, and Community Integration planning.

APPENDIX B: NEEDS & RESOURCES ASSESSMENT

Needs Assessment for Persons with a Disability/Mental Illness and Their Family/Significant Others

Please provide the following information. If you are not sure about a question answer the best you can. Please note that all questions refer to the person with the disability/mental illness unless the question specifically tells you differently. In most cases, you will be asked to place a check or x in a box. Sometimes you will be asked to write your answer down. If you need assistance, we will provide, free of charge, someone to help you fill out the form, please call 1-208-685-6768.

1. **Write the name of the County where you live** ______________________________________

2. **Who has the disability/mental illness?** (check all that apply)
If you, a friend, family member, or significant other or both have a disability/mental illness, **you may complete more than one survey**. Please complete one survey for each person and return all surveys as a group. If you need more copies of the survey, call 1-208-685-6768.

☐ I do
☐ Spouse
☐ Significant other
☐ Child
☐ Parent
☐ Other ___________________________________

3. **Write the age of the person with a disability/mental illness. If more than one disability/mental illness, list age for each one.**

Age at initial onset ____________
Age at 2nd onset (if applicable ____________
Age Now ____________

4. **Gender of person with disability/mental illness** ☐ Male ☐ Female

5. **What is the nature of the disability/ mental illness? If more than one disability, check all that apply.**

☐ Mental Illness
☐ Aging-related Disability
☐ Developmental disability (autism, down syndrome, cerebral palsy etc)
☐ Dementia
☐ Sensory disability (blindness, deafness, etc.)
☐ Other (Please specify) ___________________________________
☐ Traumatic brain injury
☐ Physical disability

6. **Sometimes people have other conditions because of their disability. Check any that apply.**
☐ Physical health problems
☐ Mental health problems
☐ Oral health problems

7. **Have you ever felt you were discriminated against or stigmatized by others? Check all that apply and explain.**
☐ Housing
☐ Medical Care
☐ Employment
☐ Provider serving you
☐ Transportation
☐ Other (Please specify)

Explain:____

8. Where do you live now? **(check the one that best applies)**
☐ In a house or apartment
☐ **In a nursing home**
☐ **group setting**
☐ **Homeless**
☐ **In a rehabilitation facility**
☐ **Home of care provider**
☐ **Other (please specify)**

9. Where would you like to live? **(check the one that best applies)**
☐ In a house or apartment
☐ **In a nursing home**
☐ **group setting**
☐ **Homeless**
☐ **In a rehabilitation facility**
☐ **Home of care provider**
☐ **Other: (please specify)**

10. If you live in a house, condo or apartment, do you rent or own? ☐ **Rent** ☐ **Own** ☐ **Other**

11. If you/they live in a house, condo, or apartment, who else lives there? **(check all that apply)**
☐ **No one else**
☐ **With Children**
☐ **With Parents**
☐ **With Professional Caregiver**
☐ **With Spouse**
☐ **Other:**

12. **Did you choose your roommate?** ☐ Yes ☐ No

13. **Are you happy where you are living?** ☐ Yes ☐ No

14. **Within the last 3 months, how many times have you seen your family health care provider ?** ___________times

15. **How far in miles do you travel to visit your family health care provider?** _______________miles

16. **If the person with the disability/mental illness has been hospitalized in the last year, check the type of services received and indicate the length of stay in the past year.**

☐ Have not been hospitalized

☐ Acute (for example, emergency, hospital, etc.) # of days ___________

☐ Rehabilitation Facility (inpatient or partial hospitalization) # of days ___________

☐ Nursing Home # of days ___________

☐ Other (Please specify) # of days ___________

17. **Would you/they be interested in receiving services via telehealth (two way television on the Internet)?** ☐ Yes ☐ No

18. **Did the person with the disability/mental illness receive a high school diploma, specialized training or advanced degree(s)?** ☐ Yes ☐ No

19. **Check the highest grade level completed by the person with the disability/mental illness.**

Less than 8th grade	Some High School	High School Diploma	Some College	College Graduate	Graduate Degree
☐	☐	☐	☐	☐	☐

20. **With regard to the person with the disability, what is the highest level of school you/they attended school since the onset of the disability/mental illness?**

☐ **Have not attended**

☐ **Have attended, if so which have you attended?**

☐ Elementary school ☐ Middle or junior high school

☐ High school ☐ Technical or Trade School

☐ College / university ☐ Other (please specify) ____________________

21. **Have they had a vocational or work evaluation? (**check all that apply)

☐ Nothing has been done ☐ Vocational Testing ☐ Job Counseling

☐ Job Training ☐ Job Placement ☐ Other (please specify)

22. **Has the person with the disability/mental illness worked since the onset of the disability/mental illness?** ☐ Yes ☐ No

23. **Is the person with the disability/mental illness currently working?** ☐ Yes ☐ No

Occupation ____

24. **If the person with the disability/mental illness is <u>not</u> working, why not?** (check all that apply)

☐ Inability to find work
☐ Inability to do any job
☐ Employer refused to accommodate disability
☐ Don't want to work
☐ Too young to work

☐ Inability to get hired
☐ Inadequate vocational rehabilitation services
☐ Enrolled in school/educational program
☐ Retired
☐ Other:___________________________________

3311

3312

25. **What was the total household income last year?**

☐ Less than $5,000
☐ $5,000 to $9,999
☐ $10,000 to $14,999
☐ $15,000 to $24,999
☐ $25,000 to $34,999
☐ $35,000 to $49,999
☐ $50,000 to $74,999
☐ Over $75,000

26. **What sources of income did the person with the disability/mental illness have?** (Check all that apply)

☐ Employment
☐ Legal settlement from disability
☐ Public Assistance (TAFI, county funds, AABD)
☐ Retirement income or pension
☐ Supplemental Security income (SSI)
☐ Other (Please specify)________________________
☐ Unemployment compensation
☐ Workers' compensation or other injury benefit
☐ Social Security Income (SSDI)
☐ Child Support
☐ Mate, family, friends

27. **How does the person with a disability/mental illness travel from place to place on a daily basis?** (check all that apply)

☐ Own car
☐ Public transportation
☐ With a professional caregiver
☐ Cannot get transportation
☐ Ride with family or friends
☐ Other: Specify

28. **Has the disability/mental illness changed any of the following areas?** (check all that apply)

☐ Marriage or Family
☐ Employment
☐ Living situation
☐ Medical Health
☐ Psychological Health
☐ Social Status

29.

	Poor	Below Average	Average	Above Average	Excellent
With regard to the person with the disability, how would you rate your/their quality of life <u>prior to the disability?</u>	☐	☐	☐	☐	☐
With regard to the person with the disability, how would you rate your/their quality of life <u>now?</u>	☐	☐	☐	☐	☐

30.

Kind of Service	**Type of Help**	**If you have help, are you satisfied?**	**If you want help and don't get it, why not?**

30. cont

	Need help	Receive help	Don't need help	Want more help	Don't know how to get help	Satisfied	Not satisfied	Can't afford or not insured	Can't get to it	Service denied
Housing	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Employment	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Personal Care	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Chores	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Transportation	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Speech Therapy	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Nursing	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Recreation	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Money Management	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Community Skills Training	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Occupational Therapy	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Kind of Service	**Type of Help**					**If you have help, are you satisfied?**		**If you want help and don't get it, why not?**		
Pain Management	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Physical Therapy	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Mental Health Counseling	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Nutrition	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Post Sec. Education	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Assistive Technology.	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Other:	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

If you are a person with a disability, skip to question number 38. If you are a family member, friend or significant other providing care, please continue with the next questions by listing the services YOU need. (check all that apply)

31.

Kind of Service	**Type of Help**					**If you have help, are you satisfied?**		**If you want help and don't get it, why not?**		
	Need help	Receive help	Don't need help	Want more help	Don't know how to get help	Satisfied	Not satisfied	Can't afford or not insured	Can't get to it	Service denied
Relief from providing care (respite care)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Training in how to care	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

		Poor	Below Average	Average	Above Average	Excellent
32.	**With regard to the caregiver, how would you rate your quality of life <u>prior to the disability?</u>**	☐	☐	☐	☐	☐

With regard to the caregiver, how would you rate your quality of life <u>now?</u> ☐ ☐ ☐ ☐ ☐

33. **Is the caregiver currently working?** ☐ Yes ☐ No Occupation ____

34. **Gender of caregiver.** ☐ Male ☐ Female

35. Age of Caregiver ________________________

36. **Relationship to person with disability.**

☐ Spouse	☐ Child
☐ Significant other	☐ Parent
☐ Professional Caregiver	☐ Other ______________________________________

37. **Check the highest grade level completed by the caregiver.**

Less than 8th grade	Some High School	High School Diploma	Some College	College Graduate	Graduate Degree
☐	☐	☐	☐	☐	☐

38. **Sometimes people like to provide answers other than checking boxes. Please tell us anything else that you would like to say. If you need more room, please feel free to use additional sheets of paper.**

Disability/Mental Illness Assessment
for Provider or Agency

Please provide the following information. If you are not sure about a question answer the best you can. ***If you need assistance, we will provide, free of charge, someone to help you fill out the form. Please call 1-208-685-6768 to ask for help.*** *If your organization has relevant "printed" information, please attach it to this questionnaire.*

Date

Name of Organization

Person Recording Information

CEO/Director

Contact Person

Mailing Address

Street Address

(if different from mailing)

Phone **Fax**

e-mail **Website**

12. Organization Type ☐ Public Agency ☐ **Private (for profit)** ☐ Not for profit

13. **Does your organization provide services for or reflected on your caseload Idaho individuals or families who have a disability/mental illness or who are over the age of 65 with an aging-related disability?** ☐ No, **if no, please stop here** and return the survey in the postage paid envelope ☐ **Yes, please continue**

14. **What is the total number of individuals served by your organization from January 1, 2001 – Dec. 31, 2001**

____________________________________.

What is the percentage of individuals served by your organization who have a disability/mental illness.

____

15. **Estimate what percentage of your payment from customers comes from each of the following sources:**

% Medicaid ________	% Medicare ________	% Private Insurance ________	% Other (specify) ________

16. **Indicate the number of individuals with a disability/mental illness served by your organization from Jan. 1, 2001- Dec 31, 2001. Write the number on the line according to the categories below.**

Males	________	Females	________	Children (<12)	________
Senior Citizens 65+	________	White	________	Children (13-18)	________
African American	________	Asian/Asian American	________	Hispanic	________
				Native American	________

17. **How many people work in your organization:**

Total (include all personnel) ____________________

Total who work 50% or more with persons with disabilities ________________

18. **Please estimate the hours per year staff that serve persons with a disability/mental illness.** ____

How many full-time employees (FTEs) work with persons with disability/mental illness in your program/facility? ____

How do you define FTE? (hours per week, weeks per year?) ____

~~What percentage of FTE workforce is spent on care for people with disabilities/mental illness?~~ _______________________

19. **In what county/counties does your organization offer services for individuals with disability?** (check all that apply)

☐ All ID Counties
☐ Ada
☐ Adams
☐ Bannock
☐ Bear Lake
☐ Benewah
☐ Bingham
☐ Blaine
☐ Boise
☐ Bonner
☐ Bonneville
☐ Boundary
☐ Butte
☐ Camas
☐ Canyon
☐ Caribou
☐ Cassia
☐ Clark
☐ Clearwater
☐ Custer
☐ Elmore
☐ Franklin
☐ Fremont
☐ Gem
☐ Gooding
☐ Idaho
☐ Jefferson
☐ Jerome
☐ Kootenai
☐ Latah
☐ Lemhi
☐ Lewis
☐ Lincoln
☐ Madison
☐ Minidoka
☐ Nez Perce
☐ Oneida
☐ Owyhee
☐ Payette
☐ Power
☐ Shoshone
☐ Teton
☐ Twin Falls
☐ Valley
☐ Washington

20. Do you define your role to include pain management? ☐ No ☐ Yes

21. **Does your organization have programs *specifically developed* for underserved populations (pediatrics, geriatrics, Native Americans, Hispanics, African Americans, Asians?)** ☐ No ☐ Yes

22. **Does your organization provide direct services (e.g. treatment, therapy, transportation, housing, etc.) for individuals with a disability/mental illness.** ☐ No ☐ Yes

Does your organization provide direct services (e.g. Treatment, therapy, transportation, housing, etc) for individuals who are over 65 with an aging-related disability. ☐ No ☐ Yes

23. **Does your organization provide prevention and/or health prevention services that are appropriate to your individual condition?**

☐ NO ☐ YES

24. **Does your organization provide acute medical services?**

☐ **NO** ☐ **YES (If yes, please check all that apply)**

☐ medical care
☐ Discharge planning/service coordination
☐ Dental
☐ Family education, information & training
☐ Substance abuse services
☐ Telehealth/telemedicine
☐ Psychiatry/psychology
☐ Emergency medical care
☐ Referrals to subspecialties
☐ Other (please specify) ______________________________

14. **Please check which services your agency provides and the settings that are applicable**

	In patient	Out patient	Day treat-ment	Home-based	Comm-unity reentry	Comm-unity-based	Resi-dential	Skilled nursing	Other
Acute Rehabilitation									
Self-Advocacy Training									
Assistive Technology									
Case Management									
Cognitive Therapy									
Probation/Parole Services									
Personal Care									
Community/Agency Referral									
Dental Care									
Driver Education									
Education/Special Education									
Independent Living Skills									
Neurobehavioral Treatment									
Housing									
Neuropsychology									
Nursing									
Occupational Therapy									
Orthodontics/Prosthetics									
Physical Therapy									
Pre-Vocational Services Employment, job training									
Psychiatry									
Psychology									
Social Work									
Mental Health Counseling									
Speech & Language Therapy									
Sub. Abuse Assess & Treatment									
Telehealth/Telemedicine									
Therapeutic Recreation									
Other									

15. **Are you interested in learning about telehealth/telemedicine?** ☐ Yes ☐ No

16. **Does your organization have any formal agreements with another agency or organization that serves individuals with disabilities/mental illness?**

☐ NO ☐ YES (If yes, please list)

17. **Please indicate by age how many individuals with a disability received the following services 1/1/01 to 12/31/01,**

	Infants (0-3)	Children (4-12)	Adolescents (13-17)	Adults (18-64)	Geriatrics (+65)
Prevention (define)					
Acute Medical Services					
Rehabilitation Services					
Education Services (refine)					
Employment Services					
Long-Term Community Supports					
Probation and Parole Services					

18. **Does your organization provide educational and/or training programs for persons with disabilities/mental illness?**

☐ **NO** ☐ **YES (If yes, please check all that apply)**

☐ EMS issues

☐ Services too far away for people to use

☐ Transportation difficulties

☐ Recruitment/retention problems w/staff in rural areas

☐ Few people so hard to provide services efficiently

Other (specify) ____________________

19. **Please tell us anything else that you would like to say**.

APPENDIX C: COMMUNITY DEVELOPMENT

Community Development Request for Proposals Press Release

Released by University Relations 27 December 2002

Contact: Dr. Beth Hudnall Stamm, (208) 282-4436; Dr. Leigh W. Cellucci, 208.282.5611; or visit http://www.isu.edu/irh/realchoices.htm www.isu.edu/irh/realchoices.htm.

Up to $115,000 Available for Community Development Project

Pocatello, Idaho. The Idaho State University Institute of Rural Health (ISU-IRH) has up to $115,000 of grant funds available to help an Idaho community with development activities as part of a project studying how to promote community integration and create community-based services and supports for persons with disabilities.

The Real Choices System Change Grant is designed to create enduring system change for persons of any age with a disability. The ultimate goal of the grant is to identify ways for communities to become invested in helping all Idahoans live full productive lives as active members of their communities.

The Real Choices Grant has two basic phases: Phase One includes a statewide anti-stigma campaign, development of advisory groups, and a statewide needs and resources assessment, culminating in a plan for change. Phase Two, which includes the community development project, tests and refines the plan through an effectiveness study.

The four main objectives of the grant are to increase access in all forms for people with disabilities, increase availability and adequacy of services, increase or maintain the value of services across the system, and increase or maintain the quality of service across the system.

The main goal of the Community Development project is to prepare the community for an effectiveness study that will be conducted by the ISU-IRH. The Request for Proposal for the Real Choices System Change Grant may be accessed at HYPERLINK http://www.isu.edu/irh/realchoices.htm http://www.isu.edu/irh/realchoices.htm. The deadline for submitting grant proposals is 5 p.m. Feb. 20.The grant provides up to $115,000 for a 15-month period. The project start date will be on or about Feb. 14, 2003. Activities should begin by March 10, 2003, and projects will be completed by May 31, 2004. Final reports are due by June 30, 2004

The Real Choices System Change Grant is funded through the Idaho Department of Health and Welfare Family and Community Services from the Center for Medicaid and Medicare Services (#18-P-91537/0).

For more information on the RFP or the Real Choices grant, visit the Web site listed above; contact Dr. Leigh Cellucci, project manager, (208) 282-5611 or HYPERLINK mailto:cellemil@isu.edu cellemil@isu.edu; or contact Dr. Beth Hudnall Stamm, principal investigator, (208) 282-4436 or HYPERLINK mailto:bhstamm@isu.edu bhstamm@isu.edu. Please note that e-mail is most efficient to use for initial questions.

APPENDIX D: ANTI-STIGMA CAMPAIGN

3365 Anti-Stigma Work Group: Summary & Referrals, June 25, 2002

Who are our audiences?	What do they need to know? (What is our message?)	What do we want them to do?	What are the opportunities for communication?	What are the tools that would help us communicate?	Referral *
Community as a whole	Get to know people with disabilities. Welcome them into communities.	Think accessibility & inclusivity. Think of people's abilities, not disabilities Interact naturally	Mass media Speak to community groups	Radio/TV Other free media	Appropriate for campaign
Legislators	Understand and be aware of needs of people	Pay attention to disability issues when voting.	Community groups they belong to	Personal visits Written material	Advocacy organizations, CIC education subcommittee, community development work group involve legislators in research site
Employers, co-workers, merchants, social and recreational	Focus on strengths of people Appropriate access and marketing	Hire people; Review inclusion/access issues Offer services/programs and market them	Groups/agencies that know of people seeking jobs; recreation agencies	TV/Radio Other tools	Appropriate for campaign, CIC employment subcommittee
City/County officials City Planners	Increased sensitivity & awareness in decision-making	Review programs for inclusivity; Review equipment/ buildings for access; Provide funds for reasonable accommodation	Idaho Assn's cities & counties	Brochures, letters Speeches	CIC education subcommittee, community development work group
Landlords/housing agency officials	Discrimination is against the law; Need for home ownership and rentals Lack of affordable housing	Rent or sell to people with disabilities/ long-term illnesses Review and make changes in facilities for access/inclusivity	Newsletters, meetings, direct mail	Direct mail Face-to-face discussions	CIC housing subcommittee
Transportation providers (non-profits, Medicaid)	Better transportation is a community value, makes business sense	Expand hours and routes Evaluate and make changes for accessibility/inclusivity	Existing work groups through IDOT	Consult with existing sub-committees on best methods	R-C community development work group & CIC transportation subcommittee
Faith-based organizations (churches)	People with disabilities/ long-term illnesses are part of your flock; they want to participate	Raise general awareness so interactions are more appropriate; abandon myths and/or religious biases. *Consider making church property available to meet needs (e.g., church vans used weekdays for transportation)*	Place to show a video, distribute brochures, etc.	Meet with minister/ lay leaders about addressing issues	R-C community development work group
Healthcare community (including substance abuse treatment)	People with disabilities or long-term illnesses have other illnesses like anybody else; need good preventive treatment	Take people seriously Ensure all medical needs are met; evaluate physical space/attitudes for accessibility/inclusivity	Professional associations (e.g., newsletters, conferences)	Trade/industry associations Fact sheet	CIC education subcommittee also CIC chairs for other relevant subcommittee
Education system (from infancy to adults)	Integration into educational settings; accessibility of physical space Focus on the individual needs of the person and family; all people are not the same Early identification and appropriate and timely assistance	Improve processes for IEPs; make other accommodations without IEPs. See people with disabilities as an asset to the education system Be person-centered and treat people as individuals Evaluate facilities/communication for accessibility & inclusivity	Idaho Dept of Education Professional organizations	Various free media	CIC education subcommittee
Judicial, corrections	Understand, be	Recognize people with	Pre-service	Prepare training	CIC chairs for other

and law enforcement	aware of needs of people when interacting with legal system	disabilities with sensitivity; Respond and interact appropriately Evaluate/change facilities	trainings POST Academy Magistrate meetings	curricula and market to existing training programs	relevant work group
Informal caregivers, including families	Recognize the community as a resource	Recognize the need to ask for help	At facilities where care is provided	Fact sheets to discharge planners/social workers Workplace at HR Depts.	Community development work group
Paid caregivers, group homes, supported living, etc	People you serve are people first and can contribute can be independent	Treat people with disabilities as people first	Workplace education	EIP programs, company newsletters, etc.	CIC education subcommittee
Advocates	Understand need for incentives for people with disabilities and providers to seek independent living	Advocate	Advocate through existing organizations	Newsletters, etc.	*Launch anti stigma campaign with briefing on how to use the tools*

* Referral denotes which organization/work group or subcommittee the audience and identified needs are referred to; not within the scope of the anti stigma campaign.

Pre-Test

Introduction for Telephone Survey

Hello. My name is ______________________. I am calling from the Institute of Rural Health at Idaho State University. We have a 10-15 minutes of questions to help the State of Idaho in developing better community-based services and support for persons with disabilities or long-term illnesses and their families. One goal of this project is to identify barriers to welcoming people with disabilities as they are integrated into the community. We are asking for your help to identify these barriers. The questions should take about 10-15 minutes to answer. Your participation is completely voluntary and all the answers you give will be kept strictly confidential. You have the right to choose to answer a question. If you choose not to answer, please let me know and we'll go on to the next question.

Are you willing to participate in this study?
___ YES—May we continue then?
___ NO – Thank you for your time. Goodbye.

Now, I'd like to read you a definition of disabilities that we'll use in this survey.

Disabilities are physical or mental conditions that can inhibit someone from functioning fully in society. They can affect people of all ages. Sometimes as we age, we also face age-related disabilities.

I. The following are some disabilities. As I read through the list, please answer if you've had personal experience living, working or interacting with people with the following disabilities:

1. Blindness Yes No
2. Loss of use of legs/people who use wheelchairs Yes No
3. Developmental disabilities or mental retardation Yes No
4. Mental illness Yes No
5. Traumatic Brain Injuries Yes No
6. Disabilities caused by aging Yes No
7. Disabilities caused by long-term or chronic medical problems Yes No
8. People with a hearing loss Yes No
9. Have you had personal experiences with people with any other disability? Yes No
   Please specify:____

Now I'm going to ask you to rank 9 statements. We'll take them three at a time. The first three deal with the level of comfort you have with people with disabilities. The scale is:

1 Very <u>un</u>comfortable
2 Somewhat uncomfortable
3 Neither comfortable nor uncomfortable

4 Comfortable
5 Very comfortable

II. How comfortable would you be working/going to school with someone with a disability?

1	2	3	4	5
Very uncomfortable	Somewhat uncomfortable	Neutral	Comfortable	Very comfortable

III. How comfortable would you be living next door to someone with a disability?

1	2	3	4	5
Very uncomfortable	Somewhat uncomfortable	Don't know	Comfortable	Very comfortable

IV. How comfortable would you be living with someone with a disability?

1	2	3	4	5
Very uncomfortable	Somewhat uncomfortable	Neutral	Comfortable	Very comfortable

Now I would like to ask you three questions about services to people with disabilities in your community. Please rate them:

1. Not accessible
2. Somewhat accessible
3. Neither accessible nor inaccessible
4. Accessible
5. Very accessible

V. How accessible are jobs to people with disabilities in your community?

1	2	3	4	5
Not accessible	Somewhat accessible	Don't know	Accessible	Very accessible

VI. How accessible is education to people with disabilities in your community?

1	2	3	4	5
Not accessible	Somewhat accessible	Don't know	Accessible	Very accessible

VII. How accessible is housing to people with disabilities in your community?

1	2	3	4	5
Not accessible	Somewhat accessible	Don't know	Accessible	Very accessible

Now I'd like to ask you thwo questions about things in your community. Please rank them on a scale of 1 to 5, with 1 being a lot and 5 being None:

VIII. How much discrimination is there against people with disabilities in your community?

1	2	3	4	5
A lot				None

IX. Are people in your community ever afraid of people with disabilities?

1	2	3	4	5
A lot				None

The next question can be answered Yes or No.

X. Would you be willing to volunteer to help people with disabilities? ___ Yes ___ No

We are about through. I would now like to ask you two more questions, both of which I will record just what you say. We will use your information, combined with other people like you, to help us understand people in Idaho.

XI. What do you need to know about people with disabilities?

XII. What kinds of things would help you live or work with people with disabilities more effectively?

XIII. I would like to ask you a few questions about you. I will not ask you any questions that will allow us to specifically know who you are.

What is your age: ___________
What county do you live in: ________
What is your sex ____________
Could you tell me your race or ethnic group affiliation __________________

We are at the end of this survey. Thank you for taking time to answer these questions. Idaho State University appreciates your willingness to help us out. Goodbye.

Post-Test

Introduction for Telephone Survey

Hello. My name is ______________________. I am calling from the Institute of Rural Health at Idaho State University. We have a 10-15 minutes of questions to help the State of Idaho in developing better community-based services and support for persons with disabilities or long-term illnesses and their families. One goal of this project is to identify barriers to welcoming people with disabilities as they are integrated into the community. We are asking for your help to identify these barriers. The questions should take about 10-15 minutes to answer. Your participation is completely voluntary and all the answers you give will be kept strictly confidential. You have the right to choose to answer a question. If you choose not to answer, please let me know and we'll go on to the next question.

Are you willing to participate in this study?
___ YES—May we continue then?
___ NO – Thank you for your time. Goodbye.

Now, I'd like to read you a definition of disabilities that we'll use in this survey.

Disabilities are physical or mental conditions that can inhibit someone from functioning fully in society. They can affect people of all ages. Sometimes as we age, we also face age-related disabilities.

I. The following are some disabilities. As I read through the list, please answer if you've had personal experience living, working or interacting with people with the following disabilities:

10. Blindness	Yes No
11. Loss of use of legs/people who use wheelchairs	Yes No
12. Developmental disabilities or mental retardation	Yes No
13. Mental illness	Yes No
14. Traumatic Brain Injuries	Yes No
15. Disabilities caused by aging	Yes No
16. Disabilities caused by long-term or chronic medical problems	Yes No
17. People with a hearing loss	Yes No
18. Have you had personal experiences with people with any other disability?	Yes No

Please specify:____

Now I'm going to ask you to rank 9 statements. We'll take them three at a time. The first three deal with the level of comfort you have with people with disabilities. The scale is:

1 Very <u>un</u>comfortable
2 Somewhat uncomfortable
3 Neither comfortable nor uncomfortable

4 Comfortable
5 Very comfortable

II. How comfortable would you be working/going to school with someone with a disability?

1	2	3	4	5
Very uncomfortable	Somewhat uncomfortable	Neutral	Comfortable	Very comfortable

III. How comfortable would you be living next door to someone with a disability?

1	2	3	4	5
Very uncomfortable	Somewhat uncomfortable	Don’t know	Comfortable	Very comfortable

IV. How comfortable would you be living with someone with a disability?

1	2	3	4	5
Very uncomfortable	Somewhat uncomfortable	Neutral	Comfortable	Very comfortable

Now I would like to ask you three questions about services to people with disabilities in your community. Please rate them:

1. Not accessible
2. Somewhat accessible
3. Neither accessible nor inaccessible
4. Accessible
5. Very accessible

V. How accessible are jobs to people with disabilities in your community?

1	2	3	4	5
Not accessible	Somewhat accessible	Don’t know	Accessible	Very accessible

VI. How accessible is education to people with disabilities in your community?

1	2	3	4	5
Not accessible	Somewhat accessible	Don’t know	Accessible	Very accessible

VII. How accessible is housing to people with disabilities in your community?

1	2	3	4	5
Not accessible	Somewhat accessible	Don’t know	Accessible	Very accessible

Now I’d like to ask you two questions about things in your community. Please rank them on a scale of 1 to 5, with 1 being a lot and 5 being None:

VIII. How much discrimination is there against people with disabilities in your community?

1	2	3	4	5
A lot				None

IX. Are people in your community ever afraid of people with disabilities?

1	2	3	4	5
A lot				None

The next question can be answered Yes or No.

X. Would you be willing to volunteer to help people with disabilities?

___ Yes ___ No

Now I'd like to ask you about an advertising campaign called Real Choices for people with disabilities – Embracing Everyone in our Communities. This has been on radio and television and in the newspaper over the last year.

XI. Have you heard or seen the campaign? ______ Yes _____ No

<u>If NO…. Proceed to XV</u>

If YES….

XII. Where did you see or hear the campaign?

Television ____
Radio ____
Newspaper ____
Brochure _____
Website _____
Other ____ (Please specify _____________________)

If YES ….

XIII. Did the campaign change your attitudes or behaviors about people with disabilities?

Yes ____ No ____

XIV. If YES… In what way?

____

____

____

____

We are about through. I would now like to ask you two more questions, both of which I will record just what you say. We will use your information, combined with other people like you, to help us understand people in Idaho.

XV. What do you need to know about people with disabilities?

XVI. What kinds of things would help you live or work with people with disabilities more effectively?

XVII. There are just a couple more brief questions. I would like to ask you a few questions about you. I will not ask you any questions that will allow us to specifically know who you are.

What is your age: ____________
What county do you live in: _________
What is your sex _____________
Could you tell me your race or ethnic group affiliation ____________________

We are at the end of this survey. Thank you for taking time to answer these questions. Idaho State University appreciates your willingness to help us out. Goodbye.

APPENDIX E: ECONOMIC & FINANCIAL DATA SOURCES

CMS 64 data, Center for Medicaid and State Operations, Division of Medicaid

Eiken, S, B. Burwell and M. Schaefer, Medicaid HCBS waiver Expenditures, FY

Home and Community Based Services: From Institutional Care to Self-Directed Supports and Services, Center for Medicaid and State Operations, Center for Medicare and Medicaid Services, May 2003.

Idaho State University financial accounting records, 2003 to 2006

Idaho State University Institute of Rural Health Effectiveness Study data, 2003 to 2006.

O'Brien, E. and R. Elias, Medicaid and Long-Term Care, Kaiser Commission on Medicaid and the Uninsured, Kaiser Family Foundation, May 2004.

Reester, H., Missmar, R. and A. Tumlinson, Recent Growth in Medicaid Home and Community-Based Service waivers, Kaiser Commission on Medicaid and the Uninsured, Kaiser Family Foundation, April 2004

Research and Statistics Unit, Division of Medicaid, IDHW, 2003

Research and Statistics Unit, Division of Medicaid, IDHW, 2006

Data for the study was gathered from a number of sources. Idaho Medicaid was acquired from the Idaho Division of Medicaid within the Idaho Department of Health and Welfare. The Idaho Department of Health and Welfare is the Grantee for the Real Choices Systems Change project. Data was also gathered from the Center for Medicare and Medicaid Services (CMS) Website. This source is a repository of statewide data submitted by Medicaid programs in all states and territories. This site hosts comprehensive and complex datasets that are available for download and analysis. CMS data also were used in State-by-State Medicaid analysis. Additional data was provided by the Kaiser Family Foundation's Kaiser Commission on Medicaid and the Uninsured, CMS's Division of Disabled and Elderly Health Programs, and from the Supported Living Project of the Idaho Council on Developmental Disabilities. Data were also acquired from the Medicaid HCBS Waiver Expenditures reports collected by Medstat Inc. from CMS reporting form 64. This report is required for HCBS Waiver programs approved by CMS. Smaller quantities of data from several other sources were also integrated into the study. Some estimates of expenditure and utilization were synthesized from data from different sources. Therefore, slightly different timeframes for reporting and reconciliation resulted in some estimates that are slightly variant from reported data. For example, data reported for the Idaho state Fiscal Year and the Federal Fiscal Year (aggregated for CMS reporting) reports minor differences. When possible these differences were reconciled. The estimates are intended to be used as ranges within which predicted expenditure and utilization can be calculated.

APPENDIX F: ADVISORY GROUPS & COMMITTEES

The research team would like to thank the members of the following committees for their steadfast attention and guidance during the conceptualization and completion of this project.

- Idaho Community Integration Committee (CIC)
- The Consortium for Idahoans with Disabilities (CID)
- Phase I and Phase II Community Development Committees

A great many people provided invaluable counsel. While we would like to recognize everyone individually, we are sure that we have missed names. In particular, we are grateful for the hard work of the following people, many of whom gave countless hours assisting us in developing and interpreting our research: Jim Baugh, Kelly Buckland, Earl Cook, Kathy Gneiting, Brian Harm, Marilyn Hern, Rick Huber, John Kirsch, Wendy Green Lowe, Dean Nielson, Butch Ragsdale, Amanda Smith, Paul Swatsenbarg, Ian Towend, Cheryl Tussey, and Julie Williams. We will miss our thoughtful brown bag work sessions and late night e-mails.

In addition, Centaur Creative Media, the Council on Developmental Disabilities, the Idaho Department of Health and Welfare, the Idaho Department of Transportation, and Jason and Associates all contributed time and/or money toward this project. There is no way that we can recognize each of the individual people at these organizations but without their support we would not have seen this to fruition.

APPENDIX G: COMMUNITY INTEGRATION MODEL

This is a community integration model that has been used in the Idaho Real Choices Effectiveness Study (ES). Prior to use in the ES, the model was applied in earlier versions, and modified based on qualitative feedback. The results from the ES suggest that the model has utility as a Community Integration (CI) model. Participants showed improvements in quality of life as measured by reliable and valid measures. In addition, participants generally stayed on course with their plans and often provided qualitative feedback that they appreciated the assistance provided to them through the model.

The model is described below for purposes of replication. Clearly the model description does not provide all the information necessary to begin a CI program without additional training. In addition, certain skills and resources are assumed.

This description is general. For more information about implementing the model, and to receive training, manuals, and forms, contact the Idaho State University Institute of Rural Health. Contact information may be found at www.isu.edu/irh.

Values & Assumptions in Developing an Individualized Community Integration Plan: Points for Reflection

Develop Collaborative Relationships

The importance of developing collaborative relationships cannot be overstated. There are two key classes of collaborative relationships. First, there is the important relationship between the owner of the plan and those who assist with implementing the plan. Secondly, the professionals who support implementation of the consumer's plan must have collaborative relationships with other service and support providers as well as community leaders.

Implement Assessment Strategies & Individualized Plans

All participants should receive a full assessment in order to build an individualized community integration plan. Assessment is the first step toward developing an effective CI plan. With permission from each participant, the assessments are shared with CI implementation team members and his or her social support system (including family and significant others) in order to develop the best possible plan.

Utilize Support Teams

Participants should be provided with well-developed CI teams that can assist with everything from negotiating costs and availability of services and supports to helping people move from institutional care to homes in the community.

Anticipate Financial Expenses

A successful CI program requires financial support. Assessment and planning fees are likely to exceed $2000 per participant. A general guideline might be to provide each participant with $3000–$4000 in addition to donated services from participating community groups and staff.

Services should be reimbursed from Medicaid or appropriate third-party payer when appropriate. However, if a service is not covered under the current system, but is part of the individual's plan, it should be paid by other sources. These other sources might include grant money, private donations, etc.

Maintain Accurate & Confidential Records

It is important to keep detailed, accurate, and confidential records. Community Integration team members performing the work should be aware of applicable confidentiality and patient privacies as well as informed consent, legal, and ethical issues. Protecting the confidentiality of participants should be of the highest priority.

Evaluate the Product Routinely

Successful CI programs are system-cost-neutral, have high consumer satisfaction, support persons with a disability living in more integrated settings, have successful outcomes on their service plans, have increased access, increased availability and adequacy of services, increased value, increased quality, and increased quality of life for persons with a disability. These variables should be routinely assessed using standardized measures.

Support Program Participants

Individuals of any age with a disability, long-term illness, or issues of aging who desire to change their life as a way to gain more independence and self-determination should be included, if they so choose, in CI efforts. In the case of persons having a parent or guardian, participants should be able to give informed assent and the legal guardian or parent should provide informed consent. If there is a conflict between the wishes of the person with a disability and their parent or guardian, this should be the first source of intervention. Resolution may or may not lead to changes in the person's living situation. To reach resolution, it may be necessary to involve other members of the support system, professionals, and in the most extreme situations, the court system.

Establish an Appropriate Program Location

Location is an important consideration for CI programs. For practical reasons, the professionals supporting a person's CI program should be able to meet face to face or virtually in order to plan and implement the CI program. Typically, participants would be located within approximately 50 miles of the community services and supports they wish to access, i.e., the "service area" of that community. This distance may be greatly reduced or expanded based on the population density and geography of the area in which the person with the CI program resides.

Recruit Participants Judiciously

Potential participants may indicate an interest in CI programs for a number of reasons including a desire to utilize specific services and supports, a desire to make lifestyle changes, or identified self-determination. Potential participants may be recruited through advocacy agencies, referrals by facility and healthcare personnel, newspaper ads, and other sources. It is unadvisable to force people to develop and implement a CI plan. Any care plan should be person-specific and address the hopes and desires of that person.

Obtain Informed Consent

Because the very essence of an individualized CI plan is consumer choice, participants in any CI program should be provided with full informed consent. Both adults and children should be provided the opportunity to decide whether or not they would like to be included. In the case of an adult guardianship, participants should be offered the opportunity to show their assent. Individuals who do not assent shall not be forced to participate even if the guardian requests their participation. Because of the complexity of developing and implementing a CI plan, participants should be allowed time to consider whether or not CI is right for them. For example, after having a chance to be informed about the program, potential participants should be given a minimum of 24 hours to consider participation. They should be encouraged to ask questions and to involve members of their support system in the decision making process.

Inform the Participant of the Participant Burden

It is important to remember that CI is an intensive process, not only from the standpoint of caseworkers and other staff/personnel, but also for the participants. Individuals agreeing to participate in a CI plan should be fully informed as to the level of required activity. Assessments can be lengthy. Participants should be informed that they may take several days and will be similar to the assessments common to inpatient rehabilitation settings. Assessments should be as extensive as needed, but care should be taken to use only the tools that are absolutely necessary for planning and implementation of the best possible plan for each individual given his/her resources, age, and disability. Developing a CI plan may require weeks. Implementing a plan may take weeks to months or even years. The plan may need to be adjusted based on successes or barriers to plan implementation. Ongoing process and outcome evaluation is necessary to understand how the plan is working. Implementing a CI plan can be a full-time endeavor for the person with a disability and even their family or other support system members.

Anticipate Potential Problems to Increase Program Retention

It is important to recognize and solve potential problems before they lead to drop-out and as a CI plan is implemented. Changing one's life is difficult and in the face of successive barriers or lack of support, it is unlikely that the will to persevere through change will be sustainable. In this model, participants should have multiple staff members working closely with them throughout the entire process, providing early opportunities for identification and remediation of problems that could lead to later drop-out.

Protect Participants by Appropriate & Regularized Care Support

Each participant in a CI program must receive ongoing case management. Care support visits (in person, by phone, or videoconference) should be conducted at a rate appropriate to the plan. In most cases, contact occurs at a greater rate, often several times per week, early in the CI planning and implementation stages. Follow-up visits may occur monthly or even less frequently, depending on the success of the plan implementation.

Community Integration Model Process

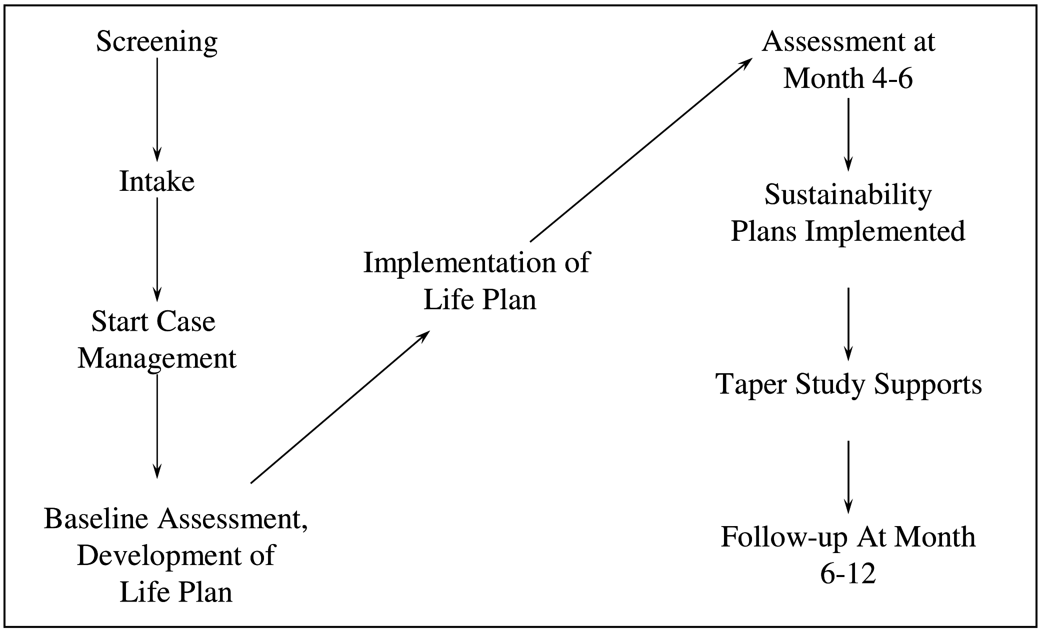
The model begins with screening. If the potential CI participant feels that the program may be right for them, CI staff can begin the process of intake, the centerpiece of which is Informed Consent. If a person chooses to proceed, the next step is Assessment, followed by the development of a CI Plan. The CI Plan is then implemented. At the end of the implementation, an additional assessment is completed to determine the quality of the CI implementation and its effects on the participant's physical and mental health and quality of life. Follow up can be ongoing or it can taper off after a time appropriate to the program and the needs of the participant.

Life-Plan Areas to Be Addressed

The CI Plan is built on seven life areas outlined in the President's New Freedom Initiative (New Freedom Commission on Mental Health, 2003), forming the basis of the life-plan developed for each participant. Because individualized plans are so important, the length of enrollment should be determined in part, by the complexity of the life plan to be implemented. The seven life areas are

(1) Housing: Transition from nursing homes/long-term care facilities to home ownership or rental of property.

Figure 10G.1. Sample Participant Flow Chart Based on a One-Year Plan



(2) Health: Personal responsibility for health implemented through a doctor appointment or other health-maintenance agreement.

(3) Information/Education: Formal schooling and public information opportunities with the potential to enrich and/or enhance life quality.

(4) Employment: Income-producing work as measured by potential for increased income, improved employment status, or job advancement that contributes to a household or community.

(5) Transportation: Establishment of responsible, reliable, and effective manner (e.g., public transportation) of getting from place to place.

(6) Self-Determination: The personal freedom to plan one's own life, the authority to control allocated resources (either through a paycheck or a benefit payment), the ability to acquire needed services and supports, the opportunity to choose what those supports are and from whom they are received, and the trust in self and in community to act responsibly.

(7) Community Support: Activities, services, supports, and other assistance designed to assist neighborhoods, communities, and individuals to be more responsive to the needs of persons with disabilities and their families.

For each of the seven life-areas, the following should be considered:

- *What does the person currently have access to, and what does he/she currently need?* Across all of the life areas, this question is best answered through personal interview. The person may wish to include other individuals such as a guardian, parent, or spouse. For example, at the interview it might be determined that a complete physical examination is needed. Additionally, participants may need consultation with specialty groups such as occupational therapy, physical therapy, and/or speech pathology. Participants may need access to programs providing training for people with disabilities on the use of the public transportation system. In terms of community support, individuals may need access to peer mentoring programs available through local organizations.

- *What is the ideal outcome?* An ideal housing outcome might be to have a stable, safe, affordable place to live. Some ideal outcomes may be too big to accomplish within the program timeframe. In these cases, goals should be set to work toward the ideal. Maintenance of a healthy lifestyle may be the ideal outcome for all participants, but identification of individualized objectives toward meeting this goal is the key. With regard to education, an ideal outcome might be for parents to enroll minors in school and maintain their attendance, as well as to obtain information pertaining to their own individualized education plan. The ideal outcome for employment may be for the participant to utilize the work incentive provisions under 1619 A&B of the Social Security Act. An ideal transportation outcome may involve assuming responsibility for one's own transportation needs. This could include the establishment of community carpools or seeking adaptive methods for personal transportation. In the area of self-determination, an ideal outcome might be the successful use of individualized budgets, personal brokers, fiscal intermediaries, and the freedom to choose these service providers. Ideal community support may consist of obtaining access to community education, personal assistance services, vehicular and home modifications, work-place support, telehealth/assistive technology, and transportation.

Remember that the power of choice belongs to the consumer and his/her family, not the professional. The individual life-plan should be built upon consumer choices, not on what team members believe to be in the consumer's best interest!

Participant's Personal Responsibility

Personal responsibility translates to personal commitment. In an ideal CI program, people will be responsible for their choices thus improving employability, promoting self-reliance, strengthening the family structure, and protecting children.

The CI program typically provides supports on a limited, short-term basis. The model is based on a theme that all people can make positive contributions to their communities, and communities are strengthened through the contributions of each individual. The CI Program participants are asked to sign a Personal Responsibility Contract defining project guidelines and serving to engage individuals in their specific plan, with the goal of assisting each person toward independence.

The ultimate goal for CI programs should involve the individual in the development of a plan to assist them toward engagement in their communities. This plan may include: (a) more complete engagement for those currently living in, but isolated from, their community, (b) assistance with "nursing home diversion" that includes working with hospital discharge planners to identify options for post-acute living, and (c) assisting participants in transitioning from institutional settings to their community. **Option selection must reside completely in the hands of the participant and/or their parent/guardian.**

Assessment

Assessment measures should be determined on case-by-case needs. Children or those adults unable to complete assessments on their own can choose to have the measures completed on their behalf by a parent or guardian. **All of the assessment measures listed below require extensive training in administration and interpretation. Those interested in the use of these instruments should have the appropriate training to administer and interpret the data. Interpretation includes making the information gathered with the tests assessable to the person with a disability and, as appropriate, their guardian, parent, or social support system members.** To plan and monitor the success of a CI program, all participants should minimally complete the following measures:

- *Stressful Life Experiences Screening* (SLES)
- *SF-12 Health Survey* (SF-12)
- *Child Behavior Checklist* (CBCL/6-1) *(if child)*
- *Functional Independence Measure*
- *The Life Status Review*

These measures are incorporated into the detailed descriptions below. Additional measures, also described below, should be used as appropriate to the age, disability, and individual participant's plan.

Overall Well Being

The Life Status Review (Stamm, et al., 1998 [LSR]) can be used as either a structured interview (e.g., for individuals with a mental illness; approximate administration time is 20–30 minutes) or as a self-report checklist (approximate administration time is 5–10 minutes). Both administrations can enhance clinical or research information by broadly summarizing a person's overall life status. The LSR provides information about potential support systems, stressors, or problem areas in the person's social environment. By tracking both problems and positive things, individuals and clinicians can identify areas of strength and weakness. Scales across life areas range from –2 (very bad) to 0 (normal for this person) to +2 (very good). The patient LSR data has an overall alpha of .93 (M=.06, SD=.7). The clinician LSR has an alpha of .84 (M=.5, SD=.7). The alpha reliabilities of the subscales range from .67–.96. The inter-scale correlations range from .14–.70 with all but 3 less than r=.45.

Psychological Assessment

Given the possible level of participant diversity in the Effectiveness Study, a number of psychological assessment tools were identified as options. Specific assessment measures were chosen from this "pool" based on the participant's age and history.

- *Structured Clinical Interview for DSM-III-R* (SCID). The SCID is a semi-structured interview typically administered by a clinician (e.g., a clinical psychologist). This measure is used to identify symptoms related to major Axis I DSM-III-R diagnoses. The SCID is made up of nine modules, seven of which represent the major axis I diagnostic classes. Results provide a record of the presence or absence of symptoms relevant to psychological disorders. Interrater reliability of the SCID is estimated to range from:.60–.84, and .85–1.00 for elderly patients.

- *Clinician-Administered PTSD Scale* (CAPS). The CAPS requires the clinician (e.g., clinical psychologist) to rate patients on each of the 17 diagnostic symptoms of Post Traumatic Stress Disorder (PTSD) as defined by the *Diagnostic and Statistical Manual of Mental Disorders, 4th edition* (1994, [DSM-IV]). Each symptom is rated in both frequency and intensity using a scale ranging from 0 to 4. A series of studies of the psychometric properties of the CAPS found that the measure had good internal consistency (alpha = 0.94), and test-retest reliability, with estimates ranging from r = .90–.98. The CAPS is considered the "gold standard" in PTSD.

- *Beck Depression Inventory-2nd ed* (BDI-II). The BDI-II is a 21-item measure designed to assess the severity of depression in adults and adolescents by self-report or clinical interview administration. The items are devised to correspond with the diagnostic criteria for depression found in the DSM-IV. Widely used in depression research, the BDI-II is reported to have alpha coefficients ranging from .86 to.92 with various clinical and non-clinical populations.
- *State Trait Anxiety Inventory* (STAI/STAI-C). The State-Trait Anxiety Inventory is a measurement tool designed to assess state (transient/temporary) versus trait (long-standing) anxiety patterns. It is available in versions appropriate for teens and adults (STAI) and children ages 9–12 years (STAI-C). The STAI contains 40 self-report Lykert items rating statements relative to personal worry, nervousness, and anxiety while the STAI-C contains only 20 such items.
- *Stressful Life Experiences Screening* (SLES). The SLES is intended for use with adults to identify life events that may be stressful. The 20-item screening tool draws on the extant literature and DSM-IV criteria for PTSD, not for the purpose of diagnoses but for identification of potentially negative experiences. Especially sensitive to change over time, the SLES is reported to have alpha reliabilities for internal consistency of at least .70 with various populations.
- *SF-12 Health Survey* (SF-12). The SF-12 is a shortened version of the SF-36. It is designed as a general measure of health focusing on eight health concepts: physical functioning, role-physical, bodily pain, general health, energy/fatigue, social functioning, role-emotional, mental health, and change in health. The SF-12 can be self-administered or given in an interview format and requires only two minutes to complete. A Mental Component Summary (MCS) score and a Physical Component Summary (PCS) score provide separate mental and physical health status results. Test-retest reliability is reported to be .89 for the PCS and .76 for the MCS.
- *Child Behavior Checklist* (CBCL/6–18). The CBCL is a 113-item measure to be completed by parents. It assesses multiple areas of a child's functioning as compared to age-based norms. Parents endorse items on a 3-point scale reporting how true each statement is with regard to their child. Results yield eight syndrome scales: Anxious/Depressed, Withdrawn/Depressed, Somatic Complaints, Social Problems, Thought Problems, Attention Problems, Rule-Breaking Behavior, and Aggressive Behavior. The measure is designed to be used with children ranging in age from 6–18.
- *Wide Range Achievement Test* (WRAT-3). WRAT-3 is a standardized measure of basic academic skills (reading, spelling, and arithmetic) and can be used with individuals age 5–74. Two equivalent forms of the WRAT-3 were developed so that an alternate form could be used at follow-up testing. Test-retest reliability ranges from .91 to .98.

Neuropsychological Assessment

Typically, neuropsychological assessment consists of an intelligence test appropriate to the age of the examinee as well as additional tests that assess brain functioning within a variety of cognitive domains (e.g., memory, visual spatial functioning, etc). With regard to community integration, these or similar tests can be administered in order to determine the nature of individual strengths, weaknesses, and/or impairment in the performance of certain cognitive tasks. **As for the tests described above, most neuropsychological instruments must be administered by an individual trained in their administration and interpretation (e.g., a clinical neuropsychologist).**

- *Wechsler Adult Intelligence Scale-3rd ed.* (WAIS-III*)*. Administration of the WAIS-III yields three composite scores (Verbal IQ, Performance IQ, Full Scale IQ) and four index scores (Verbal Comprehension, Perceptual Organization, Working Memory, Processing Speed). Scores are derived from a possible 14 subtests normed for individuals ages 16–89.

- *Wechsler Intelligence Scale for Children-3rd ed.* (WISC-III*)*. The WISC-III consists of 13 possible subtests that yield three composite scores (Verbal IQ, Performance IQ, Full Scale IQ) and four index scores (Verbal Comprehension, Perceptual Organization, Freedom from Distractibility, Processing Speed). Validity correlations with other measures of intelligence range from .65–.96 with a median of .83. The WISC-III has norms for use of the test with children ages 6–15.

- *Booklet Category Test.* The Booklet Category Test consists of 208 stimuli for which the examinee categorizes stimuli according to patterns, shapes, and numerical operations. The Booklet Category Test is designed to assess complex problem solving, judgment, abstract reasoning, and mental efficiency.

- *Tactual Performance Test.* The Tactual Performance Test is designed to assess the functional efficiency of the cerebral hemispheres separately and in cooperation. While blindfolded the examinee places blocks in corresponding positions on a form board with the dominant, non-dominant, and both hands. Results include time differentials between tasks and error patterns.

- *Trail Making Test.* Available in both an adult and child version, the Trail Making Test is designed to use perceptual skills and problem solving while maintaining fine motor speed and coordination. The task consists of drawing lines between circles labeled with alternating numerical and alphabetical stimuli. Performance results consist of time for task completion, and number of errors. Norms are provided for comparison.

Physical Therapy/Occupational Therapy Measures

- *Get-up and Go.* The Get-up and Go test measures sense of balance by assessing deviations from normal balance performance.

- *Functional Independence Measure.* The Functional Independence Measure was designed to assess degree of disability and rehabilitation outcome. The test consists of 18 tasks, each measuring degree of impairment. The test is typically used for inpatient populations.

- *Canadian Occupational Performance Measure* (COPM). The COPM was designed for occupational therapists to detect change in a client's self-perception of performance over time. It was intended for use as an outcome measure and as such, should be administered at the beginning of occupational therapy services, and again at appropriate intervals, as determined by the client and therapist.

- *Berg Balance Measure*. The Berg Balance Measure was designed to test balance in the elderly patient. The test consists of 14 items deemed safe for the elderly patient to perform.

Potential Participant Risks

It is important to assess the degree of risk for any program and to determine whether or not risks are outweighed by benefits of undertaking a CI program for any individual.

Clearly, potential health risks exist, particularly for those moving from skilled care into a community setting. In addition, CI programs are designed to bring about lifestyle changes and access to services, supports, and social connections. As a result, some participants may dislike their new lifestyle. While adjustments can be made to the plan to accommodate unexpected events or feelings, participants may find that self-determination (with appropriate services and supports) is not as expected. Additionally, family and friends may be resistant to the participant's changes, creating conflict. Finally, while participants will have a great deal of financial and personnel support during program engagement, risks may be associated with lack of sustainability if the program ceases or program participation expires.

Benefits

The benefits associated with a CI program are many. First, there is increased self determination, including increased understanding of the desires and needs of the person with a disability and their families and significant others. There often is positive change between those who provide services and supports and those who receive services and supports. Because the recipient can make direct decisions about what they need and how they wish it to be provided, there is less room for miscommunication and the ability to take corrective actions as needed. With a true CI plan, all those living in the community, including the person with a disability, their families, their social support network, and even other community members have an increased opportunity to identify and rectify barriers to true community integration. For example, if a business owner, who previously never thought about the impact of disabilities on the business's customers, watches a customer with a disability struggle with a non-assessable door, they may choose to change the door to an assessable one so that the customer can more easily patronize their business.

CI increases the probability of developing and accessing wrap-around services. It increases the potential for people to live at their peak quality of life. Theoretically, a well implemented CI plan increases individual physical and mental health reducing the potential need for costly healthcare expenditures involving hospitalizations and long-term care.

Section References

American Psychological Association. 1994. *Diagnostic and Statistical Manual of Mental Disorders:* 4th Edition. Washington, DC: Author

New Freedom Commission on Mental Health. (2003). *Achieving the Promise: Transforming Mental Health Care in America. Final Report.* Washington, DC: GPO (DHHS Publication No. SMA-03-3832). Retrieved September 20, 2005 from http://www.mentalhealthcommission.gov/reports/reports.htm

Stamm, B.H. & Rudolph, J.M., Dewane, S., Gaines, N., Gorton, K. Paul, G., McNeil, F. Bowen, G. Ercolano, M. (1996). Psychometric review of Stressful Life Experiences Screening. In B.H. Stamm (Ed.). *Measurement of Stress, Trauma and Adaptation.* Lutherville, MD: Sidran Press.

APPENDIX H: IDAHO STATE UNIVERSITY HUMAN SUBJECTS APPROVALS & INFORMED CONSENT DOCUMENTS

IDAHO STATE UNIVERSITY
HUMAN SUBJECTS COMMITTEE
NOTICE OF ACTION

RESEARCH PROPOSAL TITLE: "Real Choices System Change Grant"

INVESTIGATORS: Stamm, Piland, Kirkwood, Spearman

SPONSORING AGENCY: Idaho Department of Health and Welfare

PROPOSAL NO.: 2269MOD (Assigned by Human Subjects Committee)

HUMAN SUBJECTS COMMITTEE ACTION:

XXX PROPOSAL APPROVED AS IS

_ _ PROPOSAL APPROVED PENDING MINOR MODIFICATIONS. Submit three copies of modifications for final approval. Refer to the Manual of Policies and Procedures of the Human Subjects Committee at www.isu.edu/departments/research/human.htm for an explanation of the procedures to be followed. **Please bold all modifications.**

__ PROPOSAL REQUIRES MAJOR MODIFICATIONS. Submit 12 copies of the revised protocol for committee review. Refer to the Manual of Policies and Procedures of the Human Subjects Committee at www.isu.edu/departments/research/human.htm for an explanation of the procedures to be followed.

___ CLAIM OF EXEMPTION APPROVED

___ PROPOSAL WAS DISAPPROVED

_________________________ September 23, 2002
Human Subjects Committee Chair Date

Note: Approval is for a maximum period of one year. Projects extending beyond that time period should be renewed.

The researcher must notify the Human Subjects Committee immediately in cases where the subject is harmed. Information (e.g. adverse reactions, unexpected events/outcomes) that may impact on the risk/benefit ratio should also be reported to, and reviewed by the HSC to ensure adequate protection of the welfare of the subjects.

_X_ Investigator
_X_ Dean of Research
_X_Office of Sponsored Programs
_X_Human Subjects Committee

Date: September 23, 2002

Dear Dr. Stamm:

The Human Subjects Committee has reviewed your proposal and has given it final approval. To maintain our permission from the Federal government to use human subjects in research, certain reporting processes are required. As the principal investigator on this project, you have the responsibility to:

a. Provide the Human Subjects Committee a letter from the agency where the research will take place (if such letter was required by the Human Subjects Committee) within 14-days of the receipt of this letter. Letters from agencies should be submitted if the research is being done in (a) a hospital, in which case you will need a letter from the hospital administrator, (b) a school district, in which case you will need a letter from the superintendent, as well as the principal of the school where research will be done, or (c) a facility which has its own Institutional Review Board, in which case you will need a letter from the chair of that Board.

b. Report to the Human Subjects Committee any deviations from the methods and procedures outlined in your original protocol. If you find that modifications of methods or procedures are necessary, please report these to the Human Subjects Committee before proceeding with data collection.

c. Submit progress reports on your project every six months. You should report how many subjects have participated in the project and verify that you are following the methods and procedures outlined in your approved protocol.

d. Report to the Human Subjects Committee that your project has been completed. You should provide a short progress report to the Human Subjects Committee in which you provide information about your subjects, procedures to ensure confidentiality, and the final disposition of the data.

e. Submit a renewal of your project to the Human Subjects Committee if the project extends beyond one-year from the date of approval.

The Human Subjects Committee will contact you approximately 30 days in advance of the renewal date of your project. At that time, you will need to do (c) or (d), depending on the status of your project. Your timely response to the request for progress reports and/or project renewals will be appreciated.

Sincerely,

David Sorensen, PhD
Chair, Human Subjects Committee

Real Choices Research Study Informed Consent

Idaho State University

We are asking for your help with learning about services, supports and attitudes there are about persons with a disability in Idaho. The Institute of Rural Health at Idaho State University is conducting research to help assist the State of Idaho in developing better services and support for persons with disabilities and their families. If you would like to assist, please help us with this our surveys and focus groups. Your responses are anonymous and no data will be reported in such a way that any one individual would be identifiable.

MAILED VERSION

If you are willing to participate in this project, *please complete the survey and place it in the enclosed envelope, seal it and put it in the mailbox by (date) for delivery to Idaho State University. This paper is for you to keep for your records.* If you would like more information about the research or have questions about the survey or focus groups, please contact Dr. Beth Hudnall Stamm, Ph.D., by e-mail bhstamm@isu.edu or phone 208.282.4436.

WEB VERSION

If you are willing to participate in this project, please complete the survey *here at our website. Print out this paper is for you to keep for your records.* If you would like more information about the research or have questions about the survey or focus groups, please contact Dr. Beth Hudnall Stamm, Ph.D., by e-mail bhstamm@isu.edu or phone 208.282.4436.

PHONE VERSION

If you are willing to participate in this project, *you can answer the questions I will ask you here on the phone.* If you would like more information about the research or have questions about the survey or focus groups, please contact Dr. Beth Hudnall Stamm, Ph.D., by e-mail bhstamm@isu.edu or phone 208.282.4436.

FOCUS GROUP VERSION

If you are willing to participate in this project, *you stay here with the group and participate in the discussion.* You will be shown some television commercials and asked to participate in a discussion about them. The discussions will be audiotaped. If you would like more information about the research or have questions about the survey or focus groups, please contact Dr. Beth Hudnall Stamm, Ph.D., by e-mail bhstamm@isu.edu or phone 208.282.4436.

To assure your confidentiality, please do not write your name anywhere on the survey. If you have any questions, or would like assistance completing the survey, please contact the Brain Injury Association of Idaho at 888.374.3447 or 208.342.0999.

If you have any questions pertaining to this work, or your rights as someone participating in this study, you may contact the survey manager, Russell C. Spearman, at (208.685.6767); the focus group manager, Ann D. Kirkwood at (208.685.676?) or Dr. Beth Hudnall Stamm, the Principal Investigator for the project at (208.282.4436).

If you would like information about the project, you can find periodic updates, including a summary of this survey, posted at www.isu.edu/irh or by calling 208.282.4436.

We thank you and greatly appreciate your participation.

IDAHO STATE UNIVERSITY
HUMAN SUBJECTS COMMITTEE
NOTICE OF ACTION

RESEARCH PROPOSAL TITLE: "Real Choices System Change Grant"

INVESTIGATORS: Stamm, Cellucci, Kirkwood, Larsen, Piland, Spearman

SPONSORING AGENCY: Idaho Department of Health and Welfare

PROPOSAL NO.: 2269MOD-ADD (Assigned by Human Subjects Committee)

HUMAN SUBJECTS COMMITTEE ACTION:

_XX_ PROPOSAL APPROVED AS IS

__ PROPOSAL APPROVED PENDING MINOR MODIFICATIONS. Submit three copies of modifications for final approval. Refer to the Manual of Policies and Procedures of the Human Subjects Committee at www.isu.edu/departments/research/human.htm for an explanation of the procedures to be followed. **Please bold all modifications.**

__ PROPOSAL REQUIRES MAJOR MODIFICATIONS. Submit 12 copies of the revised protocol for committee review. Refer to the Manual of Policies and Procedures of the Human Subjects Committee at www.isu.edu/departments/research/human.htm for an explanation of the procedures to be followed.

__ CLAIM OF EXEMPTION APPROVED

__ PROPOSAL WAS DISAPPROVED

Human Subjects Committee Chair — July 3, 2003
Date

Note: Approval is for a maximum period of one year. Projects extending beyond that time period should be renewed.

The researcher must notify the Human Subjects Committee immediately in cases where the subject is harmed. Information (e.g. adverse reactions, unexpected events/outcomes) that may impact on the risk/benefit ratio should also be reported to, and reviewed by the HSC to ensure adequate protection of the welfare of the subjects.

_X_ Investigator
_X_ Dean of Research
_X_Office of Sponsored Programs
_X_Human Subjects Committee

Date: July 3, 2003

Dear Dr. Stamm:

The Human Subjects Committee has reviewed your proposal and has given it final approval. To maintain our permission from the Federal government to use human subjects in research, certain reporting processes are required. As the principal investigator on this project, you have the responsibility to:

a. Provide the Human Subjects Committee a letter from the agency where the research will take place (if such letter was required by the Human Subjects Committee) within 14-days of the receipt of this letter. Letters from agencies should be submitted if the research is being done in (a) a hospital, in which case you will need a letter from the hospital administrator, (b) a school district, in which case you will need a letter from the superintendent, as well as the principal of the school where research will be done, or (c) a facility which has its own Institutional Review Board, in which case you will need a letter from the chair of that Board.

b. Report to the Human Subjects Committee any deviations from the methods and procedures outlined in your original protocol. If you find that modifications of methods or procedures are necessary, please report these to the Human Subjects Committee before proceeding with data collection.

c. Submit progress reports on your project every six months. You should report how many subjects have participated in the project and verify that you are following the methods and procedures outlined in your approved protocol.

d. Report to the Human Subjects Committee that your project has been completed. You should provide a short progress report to the Human Subjects Committee in which you provide information about your subjects, procedures to ensure confidentiality, and the final disposition of the data.

e. Submit a renewal of your project to the Human Subjects Committee if the project extends beyond one-year from the date of approval.

The Human Subjects Committee will contact you approximately 30 days in advance of the renewal date of your project. At that time, you will need to do (c) or (d), depending on the status of your project. Your timely response to the request for progress reports and/or project renewals will be appreciated.

Sincerely,

[illegible] / for D. Sorensen

David Sorensen, PhD
Chair, Human Subjects Committee

Idaho State University Human Subjects Committee

Informed Consent Form for Medical Research

Idaho Real Choices System Change Effectiveness Study

You are asked to participate in a research study conducted by Dr. Beth Hudnall Stamm, Ph.D., Principal Investigator and Drs. Leigh W. Cellucci, Debra Larsen, and Neill F. Piland of the Pocatello office of the Institute of Rural Health and Ms. Ann K. Kirkwood, Mac and Mr. Russell C. Spearman, M.Ed. of the Boise office of the Institute of Rural Health at Idaho State University. Funding for this study is provided through the Idaho Department of Health and Welfare Family and Community Services with a grant from the Center for Medicaid and Medicare Services (#18-P-91537/0).

You have been asked to participate in this research because of you or your family member's disability. We anticipate recruiting between eighteen (18) and forty-five (45) children, adults, and older adults to enroll in this research project. Your participation in this study is entirely voluntary. You should read the information below, and ask questions about anything you do not understand, before deciding whether or not to participate.

1. PURPOSE OF THE STUDY

The purpose of this study is to test the satisfaction, quality, and value of services and supports for people with disabilities that enables them to exercise self-determination and increase their community integration.

2. PROCEDURES

If you volunteer to participate in this study, we would ask you to do the things listed below. Your handouts, which explain an individual's progress through the study and the activities of the study, should help you understand what will happen if you volunteer.

STUDY ACTIVITIES

a. *You will be asked to work with the research team and your case manager.* Your case manager is a person who works especially with you and your family. They will help you with any questions or concerns that you have. You will see them often, sometimes every week.

b. *You will be asked to take cognitive, skills, physical, and psychological tests.* This is called *assessment.* Some assessments will be the same for each participant and others will be selected just for you based on your needs and resources. You will be tested when you enroll in the study, and every 3 months until you exit the study. A few very short tests will be done weekly or monthly. The tests may be like in school, where you answer questions, or they may be more like sports where you demonstrate your ability to do tasks. They may be medical tests like your doctor gives you. You will not be graded on any of our tests! You should just do the best you can.

c. *You will be asked to help design a personalized plan for your community integration*. Your community integration plan is the research *treatment* in this study. You and your family, if appropriate, will work together with us to help figure out a plan to help you do your best at living well in your community. You will be able to try new things to help you live your life the best you can at school, in your family and your community. You can always talk to your family or your case manager about how things are going for you.

d. *You will be asked to sign a Personal Responsibility Contract* that will define your role in your individualized community integration plan.

e. *You will be asked to sign an authorization for release of information* for purposes of the research. Your information will be kept confidential.

RESEARCH GROUP ASSIGNMENT

a. For purposes of data analysis, your case will be assigned to a research group that matches with your age (child, adult or older adult) and your type of disability (physical, developmental, mental, or long-term illness). You will probably not meet the other people in your research group as these groups are for statistical purposes.

b. In this research study, all participants receive the study *treatment,* that is, your *community integration plan.* No participants will receive a *placebo*, or inactive treatment. No participants will be randomly assigned to any group since every participant will have a chance to have a *treatment* which is their community integration plan implementation.

c. *In order to have a comparison group, we will use what is called a "wait-list-comparison"* design. Each participant will experience a waiting time of a few weeks to a few months between your assessments (tests) and the implementation of your community integration plan. The length of the wait will be determined by your assessments and your plan. During this waiting time, we will continue to monitor your progress so that we can compare your satisfaction and life status before and after the implementation of your plan.

3. **POTENTIAL RISKS OR DISCOMFORTS**

For most participants, this project will involve minimal risk compared to activities normally encountered by people with disabilities. These risks are not different than those faced by people with disabilities under ordinary circumstances when they choose to make changes in their lives utilizing the existing system.

It is important for you to know that the community integration *treatment* may involve risks that are currently unforeseeable.

POTENTIAL RISKS

a. *Some tests and assessments could involve risks.* For example, if you need to have a standard medical test, the normal risk associated with those tests would apply. In the case of assessment risks, the qualified health professional who will be administering the test will discuss the risks with you and allow you to give consent for that specific test. If you choose not to have a particular test, that is your right as a participant in this research study.

b. *Your family and friends may be resistant to the changes in your life*. Because of this conflict could arise.

c. *You may find it difficult to sustain your lifestyle change after the* study. During the study, you will have a great deal of financial and personnel supports. It may be difficult for you to sustain these changes after the study is over.

d. *You may loose your current placement if you choose to try different services and supports.* Your current services and supports may not be available to you if you decide that you would like to return to your current lifestyle following the research study.

POTENTIAL DISCOMFORTS

e. *Sometimes when you try something new, it does not turn out as you expected* and it may make you feel unhappy. We want you to know about that before you agree to be in our study. For example, some of the things you want to try may not work out as well as you had hoped. For example, you may decide that you want to try to join a community activity and then find that you do not fit in very well. This could make you unhappy. You may agree to do things for yourself that you have not tried before and that may make you feel scared. Your family and your case manager will help you as best they can, but it is important for you to realize that sometimes when we try new things they do not always work out the way we hoped.

f. *Changing your living situation could involve risks.* Your community integration plan will be designed to bring about changes in your lifestyle and access to services, supports, and social connections. There are risks that you may not like your new lifestyle. While adjustments can be made to your plan to accommodate unexpected events or feelings, you may find that self-determination (with appropriate services and supports) is different than you imagined it would be.

4. **ANTICIPATED BENEFITS TO PARTICIPANTS**

Based on experience with community integration, for other people with disabilities, researchers believe it may be of benefit to people like you and may have fewer negative unintended consequences when compared to living in an institution. Of course, because individuals respond differently to changes in their lives, no one can know in advance if it will be helpful in your particular case. The potential benefits can include the following things.

POTENTIAL BENEFITS FOR YOU

a. *You will receive a full functional assessment*, with ongoing assessment and outcome evaluation, with is estimated to be between $1000 and $5000 in value

b. *You will have the opportunity to work with professionals to evaluate your life* and discuss their options for self-determination, leading to a complex and comprehensive life plan.

c. *Sometimes when we try new things, they are better than we expected.* For example, you might try a new activity in the community and find out you really like it and that you are good at it.

d. *You will have the necessary services and supports* to implement, evaluate, and adjust your community integration plan. Services and supports that are part of the identified life plan, and not available through the existing private, state or federal services and support system will be provided, within the constraints of the overall project budget, by the study. We anticipate that the overall value of services and supports for an average participant will be about $10,000 during the 6-12 month participation period.

e. *Your services and support providers may be able to identify alternative methods to help you be physically and psychologically stronger.*

f. *You may find that you can do more things for yourself* than you expected.

g. *You may find that you can contribute more* to your family, or your school, or even your town.

h. *You may find your finances are improved* as a result of community living.

i. *You may find that you have more social interaction* opportunities.

j. *You may be able to seek employment.*

5. ANTICIPATED BENEFITS TO SOCIETY

Sometimes when we try new things and keep careful watch over how they happen and compare them to the way we normally do things, we can learn how to do things better. What we learn in this study may help other people like you. For example, if you find that you are happy with part of your plan, we might be able to help others do things like you did and that could help them too.

The greatest anticipated benefit from this research is information about how to design further studies that measure the efficacy of helping people with disabilities like you move into more integrated settings in accord with their wishes.

a. *We anticipate being able to learn whether community integration,* when people have access to the services and supports that they need to be successful, is more or less expensive than living in a long-term care facility.

b. *We also hope to learn about the barriers* people who choose community integration will face and how best to remove or reduce those barriers.

c. *We hope to learn what types of plans* work best for what types of disabilities and age groups.

d. *We hope to be able to compare the differences in the patterns* of transition for people with different disabilities across different age group.

6. ALTERNATIVES TO PARTICIPATION

If you choose not to participate in this study, you have multiple options for obtaining services and supports.

a. *You may choose to keep your current lifestyle* and not make any changes.

b. *You may choose to work with your current services and support* providers to develop an alternative life plan with them.

c. *You may choose to use existing funding mechanisms* such as the school IDEA program, the TBI or Aged and Disabled Medicaid Waivers, or private insurance, to fund services and supports.

d. *You may choose to obtain services and supports* through the school system or via home health.

e. *If you are living with a long term, degenerative illness or a terminal illness* you may choose to minimize treatments and live your life with minimal medical or social intervention

f. *If you are living with a long term, degenerative illness or a terminal illness* you may choose to utilize other treatment alternatives such as Hospice, pain control medications, home health care or other treatments.

7. PAYMENT FOR PARTICIPATION

Participants will not be paid for participation in community integration activities but will be offered a modest honorarium for participating in assessment activities.

a. *You will be given an incentive for your participation* in the baseline, monthly and exit assessments. Incentives will include gift certificates to local area merchants, valued in amounts no greater than $5 per hour of assessment for up to $30 total in coupons for any assessment period. For example, if you completed 4 hours of assessments, they would be provided with up to $20 in gift certificates of goods. You will receive a $5 gift certificate for each monthly assessment you complete. No incentives will be provided for assessments beyond baseline, monthly, and exit assessments. The maximum amount you could receive would be $30 for baseline, $5 for each monthly assessment up to 11 months (up to $55 total), and $30 for the exit assessments. The most you could receive for participation in assessments during the study is $115.

b. *You will receive a full functional assessment*, with ongoing assessment and outcome evaluation, with is estimated to be between $1000 and $5000 in value

c. *You will have the necessary services and supports* to implement, evaluate, and adjust your community integration plan. Services and supports that are part of the identified life plan, and not available through the existing private, state or federal services and support system will be provided, within the constraints of the overall project budget, by the study. We anticipate that the overall value of services and supports for an average participant will be between $2000 and $10,000 during the 6-12 month participation period.

d. *You will be reimbursed for any study-related necessary travel expenses* if you do not have the ability to pay for them yourself. These could include expenses such as parking, bus/taxi fare, babysitting, travel companion/assistant, etc. Reimbursement will be paid using the standard state rates or local prevailing rate if a state rate does not exist.

e. *If you decide to withdraw, or if you are withdrawn from the study*, your payments for any assessment, travel or other study-related services and supports will be paid up through your withdrawal date.

f. *If you have any side effects or illnesses that you have not reported to us* at this time, we would encourage you to do so in order that we can take them into account when designing your participation in this study.

8. INFORMATION ABOUT YOUR SAMPLE GROUP

On the checklist at the end of this consent form, you are asked to let us know if you would like to receive information about the results of this study. There are two types of information you may receive:

a. General information about what this study found (or the conclusions of the study,)

b. Specific information about what the study found about your sample group

c. You may also choose not to receive any information

Research is a long and complicated process. Obtaining general information from a project may take years. Even if there is general information from a project, there may not be personal information for every participant.

9. FINANCIAL OBLIGATIONS

It is possible that Medicaid, Medicare, or your insurance will not pay for all of the treatments and tests you will receive if you participate in this research. This is because many insurance companies, HMOs, and health benefit plans do not cover experimental treatments.

You will not be billed for services that are not reimbursed by a third party payer. The study has funds set aside to pay for needed services and supports that are not reimbursed by a third-party payer.

It is impossible to guess how long this money will last. The research team will be watching the funds closely and will close study enrollment before the funds run out.

a. If you have reimbursement available for a needed service or support, these services will be billed. The study will not submit a bill on your behalf to a third-party payer without your written consent.

b. If reimbursement is *not* available for a needed service or support, as long as funding is available through the study, the study will pay for the service or support.

c. If research funds are not available for a suggested test, service or support, you will have the opportunity to discuss that in advance with the research team to identify alternatives. If the service is medically necessary, it will be reimbursed.

10. **EMERGENCY CARE AND COMPENSATION FOR INJURY**

If you are injured as a direct result of research procedures not done primarily for your own benefit, you will receive treatment at no cost. Idaho State University does not provide any other form of compensation for research injury.”

11. **PRIVACY AND CONFIDENTIALITY**

WHO WILL KNOW OF YOUR ENROLLMENT IN THE STUDY

The only people who will know that you are a research subject are members of the research team and, if appropriate, your services and support providers. No information about you, or provided by you during the research, will be disclosed to others without your written permission, except (a) if necessary to protect your rights or welfare (for example, if you are injured and need emergency care, or (b) if required by law.

PUBLICATION AND PRESENTATION OF STUDY DATA

a. When the results of the research are published or discussed in conferences, no information will be included that would reveal your identity. Results about 1-4 people will be reported as “<5” to obscure any possible individual identification.

b. If photographs, videos, or audiotape recordings of you will be used for educational purposes, your identity will be protected or disguised by electronically changing the characteristics of your voice or image.

DATA MANAGEMENT AND ANALYSIS

Participant data will be treated as confidential data and afforded the same coverage as would be provided to protected health information under the HIPAA guidelines.

c. Case Management calls using videophones will not be encrypted, but will use point-to-point POTS (plain old telephone service) technology, which is judged by the Center for Medicaid and Medicare Services HIPAA office as appropriate for confidential communications.

d. Data will be stored in files with either electronic or physical double authentication (e.g., two passwords or two locked files if in physical space). Only authorized study personnel will have access to the data.

e. Following the completion of the data analysis for the study, all individual identifiers will be stripped from the data which will be archived for future research.

12. **PARTICIPATION AND WITHDRAWAL**

Your participation in this research is VOLUNTARY. If you choose not to participate, that will not affect your relationship with Idaho State University, or your right to health care or other services to which you are otherwise entitled. If you decide to participate, you are free to withdraw your consent and discontinue participation at any time without prejudice to your future at ISU.

13. **CONSEQUENCES OF WITHDRAWAL**

The decision to withdraw from this research may lead to the disruption of needed services and supports. Due to the potential risks of loss of services and supports, withdrawal should be gradual, for reasons of health and safety. Gradual withdrawal will allow for the identification of other services and supports to replace those provided through the study.

14. **WITHDRAWAL OF PARTICIPATION BY THE INVESTIGATOR**

The investigator may withdraw you from participating in the research if circumstances arise which warrant doing so. While every effort will be made to support your needed level of care, if you experience severe decomposition of physical or psychological health status as a result of your community integration plan, you become a danger to self or others, or if you become ill during the research, you may have to drop out, even if you would like to continue. The investigator Dr. Beth Hudnall Stamm will make the decision and let you know if it is not possible for you to continue. The decision may be made either to protect your health or your safety, or because it is part of the research plan that people who develop certain conditions may not continue to participate. If you must drop out because the investigator asks you to (rather than because you have decided on your own to withdraw), you will be paid the full amount of what you would have received for participation in assessments through the end of the study.

15. NEW FINDINGS

During the course of the study, you will be informed of any significant new findings (either good or bad), such as changes in the risks or benefits resulting from participation in the research or new alternatives to participation, that might cause you to change your mind about continuing in the study. If new information is provided you, your consent to continuing participating in the study will be re-obtained.

16. IDENTIFICATION OF INVESTIGATORS

In the event of a research related injury or if you experience an adverse reaction, please immediately contact one of the investigators listed below. If you have any questions about the research, please feel free to contact any of the researchers or the ISU Institute of Rural Health main office at 208.282.4436 and ask for someone with the study.

Dr. Beth Hudnall Stamm, PhD. Principal Investigator Research Professor Director of Telehealth Deputy Director Institute of Rural Health Campus Box 8174 Pocatello, ID 83209-8174 208.282.4436 bhstamm@isu.edu	**Dr. Leigh W Cellucci, PhD, MBA** Research Assistant Professor Institute of Rural Health Campus Box 8174 Pocatello, ID 83209-8174 208.282.5611 cellemil@isu.edu	**Ms. Ann Kirkwood, MAc** Research Associate Institute of Rural Health 12301 W. Explorer Dr #102 ISU-Boise Campus Boise, ID 83713 208.327.6786 kirkann@isu.edu
Dr. Debra Larsen, PhD Post-Doctoral Fellow Institute of Rural Health Campus Box 8174 Pocatello, ID 83209-8174 208.282.4450 larsdeb2@isu.edu	**Dr. Neill F. Piland, PhD** Professor and Director Institute of Rural Health Campus Box 8174 Pocatello, ID 83209-8174 208.282.4436 pilaneil@isu.edu	**Mr. Russell Spearman, MEd** Senior Research Associate Institute of Rural Health 12301 W. Explorer Dr #102 ISU-Boise Campus Boise, ID 83713 208.327.6767 spearuss@isu.edu

17. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have any questions regarding your rights as a research subject, you may contact the Human Subjects Committee office at 282-3811or by writing to the Human Subjects Committee at Idaho State University, Box 8116.

SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

I have read (or someone has read to me) the information provided above. I have been given an opportunity to ask questions, and all of my questions have been answered to my satisfaction. I have been given a copy of the informed consent form.

BY SIGNING THIS FORM, I WILLINGLY AGREE TO PARTICIPATE IN THE RESEARCH IT DESCRIBES.

Name of Research Subject

Signature of Research Subject Date

INFORMATION ABOUT MY SAMPLE

Please indicate by checking and initialing the category below what type of information you want to receive. It is your responsibility to let the investigator know if your address and/or telephone number changes. The contact information is in the informed consent form under “Identification of Investigators.”

- ☐ General information about what the study found.
- ☐ Specific information about what the study found about me.
- ☐ I do not want any information about my sample.

Please send the information to the following address

Street Address or PO Box

City State Zip

SIGNATURE OF INVESTIGATOR

I have explained the research to the subject or his/her legal representative, and have answered all his/her questions. I believe that he/she understands the information described in this document and freely consents to participate.

____
Name of Investigator

____
Signature of Investigator Date

SIGNATURE WITNESS

My signature as witness certifies that the subject or his/her legal representative signed the consent form in my presence as his/her voluntary act and deed.

____
Name of Witness

____
Signature of Witness Date

Idaho State University Human Subjects Committee
Informed Consent Form for Medical Research
Idaho Real Choices System Change Effectiveness Study

Your child is asked to participate in a research study conducted by Dr. Beth Hudnall Stamm, Ph.D., Principal Investigator and Drs. Debra Larsen, and Neill F. Piland of the Pocatello office of the Institute of Rural Health and Ms. Ann K. Kirkwood, MAc of the Boise office of the Institute of Rural Health at Idaho State University. Funding for this study is provided through the XXX (#XXX).

Your child or an individual you have guardianship over (your ward) have been asked to participate in this research because of their or a family member's disability. We anticipate recruiting between xxx (xx) and xxx (xx) children, youths and their families to enroll in this research project. Participation in this study is entirely voluntary. You should read the information below, and ask questions about anything you do not understand, before deciding whether or not to consent for your child or your ward participate.

18. PURPOSE OF THE STUDY

The purpose of this study is to test the satisfaction, quality, and value of services and supports for children and youths who have been exposed to a potentially traumatizing event. The goal of the study is to learn what helps these children and their families feel safe and assist them in living as a contributing member of their community.

19. PROCEDURES

If your child/ward volunteers to participate in this study, we would ask you or your child/ward to do the things listed below. Your handouts which explain an individual's progress through the study and the activities of the study should help you understand what will happen if your child/ward volunteers.

STUDY ACTIVITIES

a. *You will be asked to work with the research team and your child/ward's case manager.* The case manager is a person who works especially with you and your family. They will help you with any questions or concerns that you have. You will see them often, sometimes every week.

b. *Your child/ward will be asked to take cognitive, skills, physical, and psychological tests. You will also be asked to provide information regarding your child's/ward's abilities and behaviors.* This is called *assessment.* Some assessments will be the same for each participant and others will be selected just for your child/ward based on their needs and resources. Your child/ward will be tested when he/she enrolls in the study, and every xx until he/she exits the study. A few very short tests will be done weekly or monthly; you may be asked for information during these brief assessments. The tests for your child/ward may be like in school, where he/she answers questions, or they may be more like sports where the participant demonstrates ability to do tasks. They may be medical tests like a doctor gives. Participants will not be graded on any of our tests! Participants should just do the best they can.

c. *You will be asked to help design a personalized plan for your child's/ward's treatment*. This plan is the research *treatment* in this study. You, your child/ward and your family, if appropriate, will work together with us to help figure out a plan to help your child/ward do his/her best. They will be able to try new things to help them live their life the best they can at school, at work, in your family and in your community. You can always talk to your family or your case manager about how things are going for your child/ward.

d. *You will be asked to sign an authorization for release of information* for purposes of the research. Your child's/ward's information will be kept confidential.

RESEARCH GROUP ASSIGNMENT

d. For purposes of data analysis, your child's/ward's case will be assigned to a research group that matches with their age (child, adult or older adult). You will probably not meet the other people in this research group as these groups are for statistical purposes.

e. In this research study, all participants receive the study *treatment.* No participants will receive a *placebo*, or inactive treatment. No participants will be randomly assigned to any group since every participant will have a chance to have a *treatment* which is their plan implementation.

f. *In order to have a comparison group, we will use what is called a "wait-list-comparison"* design. Each participant will experience a waiting time of a few weeks to a few months between assessments (tests) and the implementation of the community integration plan. The length of the wait will be determined by your assessments and your plan. During this waiting time, we will continue to monitor progress so that we can compare satisfaction and life status before and after the implementation of the plan.

20. **POTENTIAL RISKS OR DISCOMFORTS**

For most participants, this project will involve minimal risk compared to activities normally encountered by people with conditions like your child/ward. These risks are not different than those faced by people with disabilities under ordinary circumstances when they choose utilizing the existing system.

It is important for you to know that the *treatment* may involve risks that are currently unforeseeable.

POTENTIAL RISKS

a. *Some tests and assessments could involve risks.* For example, if your child/ward needs to have a standard medical test, the normal risks associated with those tests would apply. In the case of assessment risks, the qualified health professional who will be administering the test will discuss the risks with you and allow you to give consent for that specific test. If you choose not to have your child/ward participate in a particular test, that is your right as a participant in this research study.

b. *Your family and friends may be resistant to the changes in your child's/ward's life*. Because of this, thus conflict could arise.

c. *You may find it difficult to sustain your child's/ward's lifestyle change after the study*. During the study, you will have supports. It may be difficult for you to sustain these changes after the study is over.

d. *Your child/ward may be sad as a result of talking about their traumatic experience.* Because of this, you may feel sad or worried. You should talk with your healthcare professional or your Case Manager if you have any concerns.

POTENTIAL DISCOMFORTS

e. *Sometimes when you try something new, it does not turn out as you expected* and it may make you or your child/ward feel unhappy. We want you to know about that before you agree to be in our study. For example, some of the things your child/ward wants to try may not work out as well as you had hoped. For example, they may decide that they want to try to join a community activity and then find that they do not fit in very well. This could make you and your child/ward unhappy. You or your child/ward may agree to do things that you have not tried before and that may make you feel scared. Your family and your case manager will help you as best they can, but it is important for you to realize that sometimes when we try new things they do not always work out the way we hoped.

f. *Changing your child's/ward's living situation could involve risks.* The community integration plan will be designed to bring about changes in your child's/ward's lifestyle and access to services, supports, and social connections. There are risks that you or your ward may not like the new lifestyle. While adjustments can be made to the plan to accommodate unexpected events or feelings, you may find that self-determination (with appropriate services and supports) is different than you imagined it would be.

21. **ANTICIPATED BENEFITS TO PARTICIPANTS**

Based on experience with community integration, for other people with disabilities, researchers believe it may be of benefit to people like you and your child/ward and may have fewer negative unintended consequences when compared to living in an institution. Of course, because individuals respond differently to changes in their lives, no one can know in advance if it will be helpful in your particular case. The potential benefits can include the following things.

POTENTIAL BENEFITS FOR YOU

a. *Your child/ward will receive a an assessment*, with ongoing assessment and outcome evaluation, with is estimated to be between $200 and $5000 in value

b. *You will have the opportunity to work with professionals to evaluate your child's/ward's life* and discuss their options for treatment.

c. *Sometimes when we try new things, they are better than we expected.* For example, your child/ward might try new things and find out he/she really likes it and is good at it.

d. *Services and support providers may be able to identify alternative methods to help your child/ward be physically and psychologically stronger.*

e. *You may find that your child/ward can do more things for yourself* than you expected.

f. *You may find that you can contribute more* to your family, or your school, or even your town.

g. *You may find your finances are improved* as a result of your ward's community living.

h. You may find that your child/ward has more social interaction opportunities.

i. *Your child or ward may be able to seek employment.*

22. **ANTICIPATED BENEFITS TO SOCIETY**

Sometimes when we try new things and keep careful watch over how they happen and compare them to the way we normally do things, we can learn how to do things better. What we learn in this study may help other people like you. For example, if you find that you are happy with part of your child's/ward's plan, we might be able to help others do things like your child/ward did and that could help them too.

The greatest anticipated benefit from this research is information about how to adapt and provide treatment for children, youths and their families living in rural, tribal or frontier areas who have experienced traumatic events.

a. *We anticipate being able to learn whether community integration,* when people have access to the services and supports that they need to be successful, is more or less expensive than living in a long-term care facility.

b. *We also hope to learn about the barriers* people who choose community integration will face and how best to remove or reduce those barriers.

c. *We hope to learn what types of plans* work best for what types of disabilities and age groups.

d. *We hope to be able to compare the differences in the patterns* of transition for people with different disabilities across different age group.

23. ALTERNATIVES TO PARTICIPATION

If you choose not to participate in this study, you have multiple options for obtaining services and supports.

a. *You may choose to keep your child's/ward's current lifestyle* and not make any changes.

b. *You may choose to work with your child's/ward's current services and support* providers to develop an alternative life plan with them.

c. *You may choose to use existing funding mechanisms* such as the school IDEA program, the TBI or Aged and Disabled Medicaid Waivers, or private insurance, to fund services and supports.

d. *You may choose to obtain services and supports* through the school system or via home health.

e. *If your child/ward is living with a long term, degenerative illness or a terminal illness* you may choose to minimize treatments and live with minimal medical or social intervention

f. *If your child/ward is living with a long term, degenerative illness or a terminal illness* you may choose to utilize other treatment alternatives such as Hospice, pain control medications, home health care or other treatments.

24. PAYMENT FOR PARTICIPATION

Participants will not be paid for participation in community integration activities but will be offered a modest honorarium for participating in assessment activities.

a. *Your child/ward will be given an incentive for your participation* in the baseline, monthly and exit assessments. Incentives will include gift certificates to local area merchants, valued in amounts no greater than $5 per hour of assessment for up to $30 total in coupons for any assessment period. For example, if they completed 4 hours of assessments, they would be provided with up to $20 in gift certificates of goods. They will receive a $5 gift certificate for each monthly assessment they complete. No incentives will be provided for assessments beyond baseline, monthly, and exit assessments. The maximum amount a participant could receive would be $30 for baseline, $5 for each monthly assessment up to 11 months (up to $55 total), and $30 for the exit assessments. The most anyone could receive for participation in assessments during the study is $115.

b. *Your child/ward will receive a full functional assessment*, with ongoing assessment and outcome evaluation, with is estimated to be between $1000 and $5000 in value

c. *Your child/ward will have the necessary services and supports* to implement, evaluate, and adjust your community integration plan. Services and supports that are part of the identified life plan, and not available through the existing private, state or federal services and support system will be provided, within the constraints of the overall project budget, by the study. We anticipate that the overall value of services and supports for an average participant will be between $2000 and $10,000 during the 6-12 month participation period.

d. *You will be reimbursed for any study-related necessary travel expenses* if you do not have the ability to pay for them yourself. These could include expenses such as parking, bus/taxi fare, babysitting, travel companion/assistant, etc. Reimbursement will be paid using the standard state rates or local prevailing rate if a state rate does not exist.

e. *If you decide to withdraw, or if you are withdrawn from the study*, your payments for any assessment, travel or other study-related services and supports will be paid up through your withdrawal date.

f. *If your child/ward has any side effects or illnesses that you have not reported to us* at this time, we would encourage you to do so in order that we can take them into account when designing participation in this study.

25. INFORMATION ABOUT YOUR SAMPLE GROUP

On the checklist at the end of this consent form, you are asked to let us know if you would like to receive information about the results of this study. There are two types of information you may receive:

a. General information about what this study found (or the conclusions of the study,)

b. Specific information about what the study found about your child's/ward's sample group

c. You may also choose not to receive any information

Research is a long and complicated process. Obtaining general information from a project may take years. Even if there is general information from a project, there may not be personal information for every participant.

26. FINANCIAL OBLIGATIONS

It is possible that Medicaid, Medicare, or your child's/ward's insurance will not pay for all of the treatments and tests your child/ward will receive if they participate in this research. This is because many insurance companies, HMOs, and health benefit plans do not cover experimental treatments.

You and your ward will not be billed for services that are not reimbursed by a third part payer. The study has funds set aside to pay for needed services and supports that are not reimbursed by a third-party payer.

It is impossible to guess how long this money will last. The research team will be watching the funds closely and will close study enrollment before the funds run out.

a. If your child/ward has reimbursement available for a needed service or support, these services will be billed. The study will not submit a bill on their behalf to a third-party payer without your written consent.

b. If reimbursement is *not* available for a needed service or support, as long as funding is available through the study, the study will pay for the service or support.

c. If research funds are not available for a suggested test, service or support, you will have the opportunity to discuss that in advance with the research team to identify alternatives. If the service is medically necessary, it will be reimbursed.

27. **EMERGENCY CARE AND COMPENSATION FOR INJURY**

If you are injured as a direct result of research procedures not done primarily for your own benefit, you will receive treatment at no cost. Idaho State University does not provide any other form of compensation for research injury.”

28. **PRIVACY AND CONFIDENTIALITY**

WHO WILL KNOW OF YOUR ENROLLMENT IN THE STUDY

The only people who will know that your child/ward is a research subject are members of the research team and, if appropriate, your service and support providers. No information about your child/ward or provided by you during the research will be disclosed to others without your written permission, except (a) if necessary to protect your rights or welfare (for example, if you are injured and need emergency care, or (b) if required by law.

PUBLICATION AND PRESENTATION OF STUDY DATA

a. When the results of the research are published or discussed in conferences, no information will be included that would reveal your child’s/ward’s identity. Results about 1–4 people will be reported as “<5” to obscure any possible individual identification.

b. If photographs, videos, or audiotape recordings of your child/ward will be used for educational purposes, identity will be protected or disguised by electronically changing the characteristics of the voice or image.

DATA MANAGEMENT AND ANALYSIS

Participant data will be treated as confidential data and afforded the same coverage as would be provided to protected health information under the HIPAA guidelines.

c. Case Management calls using videophones will not be encrypted, but will use point-to-point POTS (plain old telephone service) technology, which is judged by the Center for Medicaid and Medicare Services HIPAA office as appropriate for confidential communications.

d. Data will be stored in files with either electronic or physical double authentication (e.g. two passwords or two locked files if in physical space). Only authorized study personnel will have access to the data.

e. Following the completion of the data analysis for the study, all individual identifiers will be stripped from the data which will be archived for future research.

29. **PARTICIPATION AND WITHDRAWAL**

Your child's/ward's participation in this research is VOLUNTARY. If you choose not to consent to their participation, that will not affect your relationship with Idaho State University or your right to health care or other services to which you are otherwise entitled. If you decide to have your child/ward participate, you are free to withdraw your consent and discontinue participation at any time without prejudice to your future at ISU.

30. **CONSEQUENCES OF WITHDRAWAL**

The decision to withdraw from this research may lead to the disruption of needed services and supports. Due to the potential risks of loss of services and supports, withdrawal should be gradual, for reasons of health and safety. Gradual withdrawal will allow for the identification of other services and supports to replace those provided through the study.

31. **WITHDRAWAL OF PARTICIPATION BY THE INVESTIGATOR**

The investigator may withdraw your child/ward from participating in the research if circumstances arise which warrant doing so. While every effort will be made to support the needed level of care, if your child/ward experiences severe decomposition of physical or psychological health status as a result of the community integration plan, they become a danger to self or other, or if they become ill during the research, they may have to drop out, even if you would like to have them continue. The investigator Dr. Beth Hudnall Stamm will make the decision and let you know if it is not possible for your child/ward to continue. The decision may be made either to protect your health or your safety or because it is part of the research plan that people who develop certain conditions may not continue to participate. If your child/ward must drop out because the investigator asks them to (rather than because you have decided on your own to withdraw), they will be paid the full amount of what they would have received for participation in assessments through the end of the study.

32. NEW FINDINGS

During the course of the study, you and your child/ward will be informed of any significant new findings (either good or bad), such as changes in the risks or benefits resulting from participation in the research or new alternatives to participation, that might cause you to change your mind about continuing in the study. If new information is provided you, your consent to continuing participating in the study will be re-obtained.

33. IDENTIFICATION OF INVESTIGATORS

In the event of a research related injury or if you experience an adverse reaction, please immediately contact one of the investigators listed below. If you have any questions about the research, please feel free to contact any of the researchers or the ISU Institute of Rural Health main office at 208.282.4436 and ask for someone with the study.

Dr. Beth Hudnall Stamm, PhD. Principal Investigator Research Professor Director of Telehealth Deputy Director Institute of Rural Health Campus Box 8174 Pocatello, ID 83209-8174 208.282.4436 bhstamm@isu.edu	**Dr. Leigh W Cellucci, PhD, MBA** Research Assistant Professor Institute of Rural Health Campus Box 8174 Pocatello, ID 83209-8174 208.282.5611 cellemil@isu.edu	**Ms. Ann Kirkwood, MAc** Research Associate Institute of Rural Health 12301 W. Explorer Dr #102 ISU-Boise Campus Boise, ID 83713 208.327.6786 kirkann@isu.edu
Dr. Debra Larsen, PhD Post-Doctoral Fellow Institute of Rural Health Campus Box 8174 Pocatello, ID 83209-8174 208.282.4450 larsdeb2@isu.edu	**Dr. Neill F. Piland, PhD** Professor and Director Institute of Rural Health Campus Box 8174 Pocatello, ID 83209-8174 208.282.4436 pilaneil@isu.edu	**Mr. Russell Spearman, MEd** Senior Research Associate Institute of Rural Health 12301 W. Explorer Dr #102 ISU-Boise Campus Boise, ID 83713 208.327.6767 spearuss@isu.edu

34. I RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have any questions regarding your rights as a research subject, you may contact the Human Subjects Committee office at 282-3811 or by writing to the Human Subjects Committee at Idaho State University, Box 8116.

SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

I have read (or someone has read to me) the information provided above. I have been given an opportunity to ask questions, and all of my questions have been answered to my satisfaction. I have been given a copy of the informed consent form.

BY SIGNING THIS FORM, I WILLINGLY AGREE TO PARTICIPATE IN THE RESEARCH IT DESCRIBES.

____
Name of Research Subject

____
Signature of Research Subject Date

INFORMATION ABOUT MY SAMPLE

Please indicate by checking and initialing the category below what type of information you want to receive. It is your responsibility to let the investigator know if your address and/or telephone number changes. The contact information is in the informed consent form under "Identification of Investigators."

☐ General information about what the study found.
☐ Specific information about what the study found about me.
☐ I do not want any information about my sample.

Please send the information to the following address

____
Street Address or PO Box

____
City State Zip

SIGNATURE OF INVESTIGATOR

I have explained the research to the subject or his/her legal representative, and have answered all his/her questions. I believe that he/she understands the information described in this document and freely consents to participate.

Name of Investigator

Signature of Investigator Date

SIGNATURE WITNESS

My signature as witness certifies that the subject or his/her legal representative signed the consent form in my presence as his/her voluntary act and deed.

Name of Witness

Signature of Witness Date

Idaho State University Human Subjects Committee

ADULT ASSENT FORM

Idaho Real Choices System Change Effectiveness Study

35. *My name is*____

36. *We are asking you to take part in a research study* because we want to learn about how to help people with disabilities live their lives the best ways that they can. By disabilities, we mean people who have special needs. They may be blind, need a wheelchair, or feel sad a lot, or they may have been sick for a long time. For example, we would like to learn about how people with disabilities can go to school, have jobs, participate in activities in their town, get healthcare, and live in a place that they choose.

37. *If you agree to be in this study* you, your guardian and your family will work with us for 6 to 9 months, about the same length of time as a school year.

    a. *You will have a case manager.* Your case manager is a person who works especially with you, your guardian and your family. They will help you with any questions or concerns that you have. You will see them often, sometimes every week.

    b. *You will also take some tests.* The tests may be like in school, where you answer questions, or they may be more like sports where you do stuff like show us how far you can throw a ball or pick things up. They may be tests like your doctor gives you. You don't have to worry; you won't be graded on any of our tests! You should just do the best you can.

    c. *You will have a plan for trying new things*. You, your guardian and your family will work together with us to help figure out a plan to help you do your best. You will get to try new things to help you live your life the best you can at work, in your family and your community. You can always talk to your family, your guardian or your case manager about how things are going for you.

38. *Sometimes when you try new things, stuff you don't expect happens* and it may make you feel unhappy. We want you to know about that before you agree to be in our study. For example, you may decide that you want to try to join a club and then find that you don't fit in very well. This could make you unhappy. You may agree to do things for yourself that you have not tried before and that may make you feel scared. Your family, your guardian and your case manager will help you as best they can, but it is important for you to realize that sometimes when we try new things they don't always work out the way we hoped.

39. *Sometimes when we try new things, they are better than we expected*. For example, you might try a new activity and find out you really like it and that you are good at it. You may work with new health care professionals who help you learn new things. You may find that you can do more things for yourself or contribute more to your family, or your school, or even your town.

40. *Sometimes when we try new things and keep careful watch over how they happen*, we can learn things that will help other people like you. For example, if you find that you are happy with part of your plan, we might be able to help others do things like you did and that could help them too. By working with you and your family, we may learn more about how to pay for doctor bills and other things that people like you need to do their best.

41. *We have already received permission from your guardian*(s) for you to participate in this research. Even though your guardian(s) have given permission, you still can decide for yourself if you want to participate.

42. *If you don't want to be in this study, you don't have to be*. Remember, being in this study is up to you and no one will be upset if you don't want to participate or even if you change your mind later and want to stop.

43. *You can ask any questions that you have* about the study. If you have a question later that you didn't think of now, you can ask it later.

44. *Signing below means that you agree to be in the study*. You, your parent(s) and/or guardian will be given a copy of this form after you have signed it.

Participant Signature ______________________________ Date ____________

Participant Name (Print) ______________________________

Researcher Signature ______________________________ Date ____________

Parent Name (Print) ______________________________

Witness Signature ______________________________ Date ____________

Witness Name (Print) ______________________________

Idaho State University Human Subjects Committee

YOUTH ASSENT FORM (AGE 13-17)

Idaho Real Choices System Change Effectiveness Study

45. *My name is*____

46. *We are asking you to take part in a research study* because we want to learn about how to help people with disabilities live their lives the best ways that they can as members of their communities. By disabilities, we mean people who have special needs. They have a physical disability, or a developmental disability, or have a mental illness, or they may have a long-term illness. For example, we would like to learn about how people with disabilities can go to school, have jobs, participate in activities in their town, get healthcare, and live in a place that they choose.

47. *If you agree to be in this study* you and your family will work with us for 6 to 9 months, about the same length of time as a school year.

   a. *You will have a case manager.* Your case manager is a person who works especially with you and your family. They will help you with any questions or concerns that you have. You will see them often, sometimes every week.

   b. *You will also take some tests.* The tests may be like in school, where you answer questions, or they may be more like sports where you do stuff like show us how far you can throw a ball or pick things up. They may be tests like your doctor gives you. You don't have to worry; you won't be graded on any of our tests! You should just do the best you can.

   c. *You will have a plan for trying new ways to live in your community*. You and your family will work together with us to help figure out a plan to help you do your best at living well in your community. You will get to try new things to help you live your life the best you can at school, in your family and your community. You can always talk to your family or your case manager about how things are going for you.

48. *Sometimes when you try new things, stuff you don't expect happens* and it may make you feel unhappy. We want you to know about that before you agree to be in our study. For example, some of the things you want to try may not work out as well as you had hoped. For example, you may decide that you want to try to join a club at school and then find that you don't fit in very well. This could make you unhappy. You may agree to do things for yourself that you have not tried before and that may make you feel scared. Your family and your case manager will help you as best they can, but it is important for you to realize that sometimes when we try new things they don't always work out the way we hoped.

49. *Sometimes when we try new things, they are better than we expected*. For example, you might try a new activity at school and find out you really like it and that you are good at it. You may work with new health care professionals who help you learn new things or better ways to be physically and psychologically strong. You may find that you can do more things for yourself or contribute more to your family, or your school, or even your town.

50. *Sometimes when we try new things and keep careful watch over how they happen* and compare them to the way we normally do things, we can learn how to do things better. What we learn in this study may help other people like you. For example, if you find that you are happy with part of your plan, we might be able to help others do things like you did and that could help them too. By working with you and your family, we may learn more about how to pay for doctor bills and things that people like you need to do their best.

51. *We have already received permission from your parent*(s) for you to participate in this research. Even though your parent(s) have given permission, you still can decide for yourself if you want to participate.

52. *If you don't want to be in this study, you don't have to be*. Remember, being in this study is up to you and no one will be upset if you don't want to participate or even if you change your mind later and want to stop.

53. *You can ask any questions that you have* about the study. If you have a question later that you didn't think of now, you can ask it later.

54. *Signing below means that you agree to be in the study*. You, your parent(s) and/or guardian will be given a copy of this form after you have signed it.

Participant Signature ______________________________ Date __________

Participant Name (Print) ______________________________

Researcher Signature ______________________________ Date __________

Parent Name (Print) ______________________________

Witness Signature ______________________________ Date __________

Witness Name (Print) ______________________________

Idaho State University Human Subjects Committee

CHILD ASSENT FORM (UP TO AGE 13)

Idaho Real Choices System Change Effectiveness Study

55. *My name is*____

56. *We are asking you to take part in a research study* because we want to learn about how to help people with disabilities live their lives the best ways that they can. By disabilities, we mean people who have special needs. They may be blind, need a wheelchair, or feel sad a lot, or they may have been sick for a long time. For example, we would like to learn about how people with disabilities can go to school, have jobs, participate in activities in their town, get healthcare, and live in a place that they choose.

57. *If you agree to be in this study* you and your family will work with us for 6 to 9 months, about the same length of time as a school year.

a. *You will have a case manager.* Your case manager is a person who works especially with you and your family. They will help you with any questions or concerns that you have. You will see them often, sometimes every week.

b. *You will also take some tests.* The tests may be like in school, where you answer questions, or they may be more like sports where you do stuff like show us how far you can throw a ball or pick things up. They may be tests like your doctor gives you. You don't have to worry; you won't be graded on any of our tests! You should just do the best you can.

c. *You will have a plan for trying new things*. You and your family will work together with us to help figure out a plan to help you do your best. You will get to try new things to help you live your life the best you can at school, in your family and your community. You can always talk to your family or your case manager about how things are going for you.

58. *Sometimes when you try new things, stuff you don't expect happens* and it may make you feel unhappy. We want you to know about that before you agree to be in our study. For example, you may decide that you want to try to join a club at school and then find that you don't fit in very well. This could make you unhappy. You may agree to do things for yourself that you have not tried before and that may make you feel scared. Your family and your case manager will help you as best they can, but it is important for you to realize that sometimes when we try new things they don't always work out the way we hoped.

59. *Sometimes when we try new things, they are better than we expected*. For example, you might try a new activity at school and find out you really like it and that you are good at it. You may work with new health care professionals who help you learn new things. You may find that you can do more things for yourself or contribute more to your family, or your school, or even your town.

60. *Sometimes when we try new things and keep careful watch over how they happen*, we can learn things that will help other people like you. For example, if you find that you are happy with part of your plan, we might be able to help others do things like you did and that could help them too. By working with you and your family, we may learn more about how to pay for doctor bills and things that people like you need to do their best.

61. *We have already received permission from your parent*(s) for you to participate in this research. Even though your parent(s) have given permission, you still can decide for yourself if you want to participate.

62. *If you don't want to be in this study, you don't have to be*. Remember, being in this study is up to you and no one will be upset if you don't want to participate or even if you change your mind later and want to stop.

63. *You can ask any questions that you have* about the study. If you have a question later that you didn't think of now, you can ask it later.

64. *Signing below means that you agree to be in the study*. You, your parent(s) and/or guardian will be given a copy of this form after you have signed it.

Participant Signature ______________________ Date __________

Participant Name (Print) ______________________

Researcher Signature ______________________ Date __________

Parent Name (Print) ______________________

Witness Signature ______________________ Date __________

Witness Name (Print) ______________________

REFERENCES

American Psychological Association. 1994. *Diagnostic and Statistical Manual of Mental Disorders:* 4th Edition. Washington, DC: Author.

Bassett, J., Lloyd, C., & Bassett, H. (2001). Work issues for young people with psychosis: Barriers to employment. *British Journal of Occupational Therapy, 64*, 66-72.

Brown, K., & Bradley, L.J. (2002). Reducing the stigma of mental illness. *Journal of Mental Health Counseling, 24*, 81-87.

Charlton, J.I. (1998). *Nothing about us without us: Disability oppression and empowerment.* Berkeley: University of California Press.

Chiswick, B. (1976). The demand for nursing home care: An analysis of the substitution between institutional and non-institutional care. *Journal of Human Resources, 11*(3): 295-316.

Corrigan, P.W. (2005). *On the Stigma of Mental Illness.* Washington, DC: APA.

Corrigan, P. W., Edwards, A. B., Green, A., Diwan, S. L., & Penn, D. L. (2001a). Prejudice, social distance, and familiarity with mental illness. *Schizophrenia Bulletin, 27*, 219-22.

Corrigan, P. W., River, L. P., Lundin, R. K., Penn, D. L., Uphoff-Wasowski, K., Campion, J., et al. (2001b). Three strategies for changing attributions about severe mental illness. *Schizophrenia Bulletin*, *27*, 187-195.

Corrigan, P.W., & Watson, A.C. (2002). The paradox of self-stigma and mental illness. *Clinical Psychology: Science & Practice*, *9*, 35-53.

Crisp, R. (2000). A qualitative study of the perceptions of individuals with disabilities concerning health and rehabilitation professionals. *Disability and Society*, *15*(2), 355-367.

Crocetti, G. M., Spiro, H. R. & Siassi, I. (1974). *Contemporary attitudes toward mental illness.* Pittsburgh, PA: University of Pittsburgh Press.

Dale, S., R. Brown, B. Phillips et al. (2003) The effects of cash and counseling on personal care services and Medicaid costs in Arkansas. *Health Affairs*, W3-566, November 19.

Eiken, S, Burwell, B. & Schaefer, M. (2004). Medicaid HCBS waiver expenditures, FY 1998 through FY 2003. *Medstat*, May 20.

Finlay, W. M., Dinos, S., & Lyons, E. (2001). Stigma and multiple social comparisons in people with schizophrenia. *European Journal of Social Psychology*, *31*, 579-592.

Fishbein, M., Cappella, J., & Hornik, R. (2002). The role of theory in developing effective antidrug public service announcements. In W. D. Crano & M. Burgoon (Eds) *Mass media and drug prevention: Classic and contemporary theories and research* (89-117). Mahwah, NJ: Lawrence Erlbaum Associates.

Friere, P. (2003 [1970]). *Pedagogy of the Oppressed* 30th ed. New York: Continuum.

Haghighat, R. (2001). A unitary theory of stigmatisation: Pursuit of self-interest and routes to destigmatisation. *British Journal of Psychiatry, 178*, 207-215.

Hall, J. W., Ewing, A., & Tinzmann, M.B. (1981). Phonetic coding in dyslexics and normal readers [Comment/Reply]. *Bulletin of the Psychonomic Society*, *17*(4):177-178.

Harper, N. (1979). *Human communication theory: The history of a paradigm*. Rochelle Park, NJ: Hayden Book Company.

Henry, A.D., & Lucca, A.M. (2002). Contextual factors and participation in employment for people with serious mental illness. *Occupational Therapy Journal of Research*, *22*, 83S-84S.

Hinshaw, S.P., & Cicchetti, D. (2000). Stigma and mental disorder: Conceptions of illness, public attitudes, personal disclosure, and social policy. *Development and Psychopathology*, *12*, 555-598.

Home and Community Based Services: From Institutional Care to Self-Directed Supports and Services. (2003, May). Center for Medicaid and State Operations, Center for Medicare and Medicaid Services. Washington, DC.

Idaho Broadcasters Association (2003). Ad Hoc Report. Boise, ID.

Idaho CareLine (2006). Ad Hoc Report. Boise, ID.

Infante, D.A., Rancer, A.S., & Womack, D.F. (1990). *Building communication theory*. Prospect Heights, IL: Waveland Press.

Johnstone, M. (2001). Stigma, social justice and the rights of the mentally ill: Challenging the status quo. *Australian & New Zealand Journal of Mental Health Nursing*, *10*, 200-209.

Kilbury, R., Bordieri, J., & Wong, H. (1996, April-June). Impact of physical disability and gender on personal space. *Journal of Rehabilitation*, *59-61*.

Kiplinger Retirement Report, March 2004.

Kotler, P., & Roberto, E. (1989). *Social marketing: Strategies for changing public behavior*. New York: Free Press.

Leff, S., Conley, J., Campbell-Orde T., & V. Bradley. (2003). Getting to systems that promote self-determination through research & evaluation. National Self Determination & Psychiatric Disability Invitational Conference, Chicago, Il, Oct.

Link, B. G., Cullen, F. T., Mirotznik, J. & Struening, E. (1992). The consequences of stigma on persons with mental illness: Evidence from the social sciences in stigma and mental illness. In P. J. Fink & A. Tasman (Eds.), *Stigma and mental illness* (pp. 87-96). Washington, DC: American Psychiatric Press.

Link, B.G., Struening, E.L., Neese-Todd, S., Asmussen, S., & Phelan, J.C. (2001). Stigma as a barrier to recovery: The consequences of stigma for the self-esteem of people with mental illnesses. *Psychiatric Services*, *52*, 1621-1626.

MacStravic, S. (2000). The missing links in social marketing. *Journal of Health Communications, 5*, 255-263.

National Institutes of Alcohol Abuse & Alcoholism. (2000). *10th Special Report to the US Congress on Alcohol & Health*. Washington, DC: US Dept of Health & Human Services.

New Freedom Commission on Mental Health. (2003). *Achieving the Promise: Transforming Mental Health Care in America. Final Report*. Washington, DC: GPO (DHHS

Publication No. SMA-03-3832). Retrieved September 20, 2005 from http://www.mentalhealthcommission.gov/reports/reports.htm.

O'Brien, E., & Elias, R.. (2004). Medicaid and long-term care. Kaiser Commission on Medicaid and the Uninsured, Kaiser Family Foundation.

Penn, D. L., Guynan, K., Daily, T., Spaulding, W. D., Garbin, C. P., & Sullivan, M. (1994). Dispelling the stigma of schizophrenia: What sort of information is best? *Schizophrenia Bulletin*, *20*(3), 567-574.

Piland, N. (1978, May). Cost-effectiveness and feasibility of alternative long-term care settings. Stanford Research Institute.

Rabkin, J. (1974, Fall). Public attitudes toward mental illness: A review of the literature. *Schizophrenia Bulletin*, *10*, 9-31.

Reester, H., Missmar, R.., & Tumlinson, A. (2004, April). Recent growth in Medicaid home and community-based service waivers. Kaiser Commission on Medicaid and the Uninsured, Kaiser Family Foundation.

Robert Wood Johnson Foundation (2001, February). *Substance abuse: The nation's number one health problem*. Waltham, MA: Robert Wood Johnson Foundation.

Rosenbaum, S. (2000) Olmstead Decision: Implications for State Health Policy. *Health Affairs, 19*(5):228-232.

Rothschild, M.L. (1999). Carrots, sticks, and promises: A conceptual framework for the management of public health and social issue behaviors. *Journal of Marketing*, *63*(4):24-37.

Shapiro, T. (1999). "Between empathy and judgment": Comment. *Journal of the American Psychoanalytic Association, 47*(2): 390-395.

Stamm, B.H. (Ed.). (2003). *Behavioral Healthcare in Rural and Frontier Areas: An Interdisciplinary Handbook*. Washington, DC: American Psychological Association Press.

Stamm, B.H., & Rudolph, J.M., Dewane, S., Gaines, N., Gorton, K. Paul, G., McNeil, F. Bowen, G. Ercolano, M. (1996). Psychometric review of Stressful Life Experiences Screening. In B.H. Stamm (Ed.). *Measurement of Stress, Trauma and Adaptation.* Lutherville, MD: Sidran Press.

Stamm B.H., Rudolph M.A., Smith A. & Varra E.M. (1998) Life status review: monitoring biopsychosocial risk factors in traumatic stress. Available at: http://www.isu.edu/~bhstamm/pdf/LSR_pos.pdf

Story, C. (2003). Social Marketing. Unpublished Master's Thesis. Boise State University.

Struening, E.L., Perlick, D.A., Link, B.G., Hellman, F., Herman, D., & Sirey, J.A. (2001). Stigma as a barrier to recovery: The extent to which caregivers believe most people devalue consumers and their families. *Psychiatric Services, 52,* 1633-1638.

Substance Abuse and Mental Health Services Administration. (2001, November). Substance use among older adults. *The National Household Survey on Drug Abuse Report.*

Tandon, R.K. (1981). A study-habit survey among home science under-graduates. *Child Psychiatry Quarterly, 14*(1): 26- 31.

U.S. Census. (2000). U.S. Census. Retrieved July 28, 2006, from http://www.census.gov/popest/states/asrh/tables/SC-EST2003-03/SC-EST2003-03-16.pdf

Veltman, A., Cameron, J.I., & Stewart, D.E. (2002). The experience of providing care to relatives with chronic mental illness. *Journal of Nervous and Mental Disease, 190*(2): 108-114.

Vladeck,B. (2003). Where the Action Really Is: Medicaid and the Disabled. *Health Affairs, 22*(1): 90-100.

Wahl, O.F. (1995). *Media madness: Public images of mental illness*. New Brunswick, NJ: Rutgers University Press.

Wilson, J., & Lewiecki-Wilson, C. (Eds.). (2001). *Embodied rhetorics: Disability in language and culture*. Carbondale, IL: Southern Illinois University Press.

Yanos, P. T., Rosenfeld, S., & Horowitz, A.V. (2001). Negative and supportive social interactions and quality of life among persons diagnosed with severe mental illness. *Community Mental Health Journal, 37*(5): 405-419.

Young, I.M. (1990). *Justice and the politics of difference*. Princeton, NJ: Princeton University Press.

ACRONYM LIST

A&D-Aged and Disabled Waiver, the
ACT-Assertive Community Treatment
ADA-Americans with Disabilities Act
B2T2-Better Todays. Better Tomorrows.
BDI-*Beck Depression Inventory*
CAPS -*Clinician-Administered PTSD Scale*
CBCL-Child Behavior Checklist
CES-Consumer Experience Inventory
CD-community development
CFH-Certified Family Home
CIC-Idaho Community Integration Committee
CIP-Community Integration Program
CIQ-*Community Integration Questionnaire*
CMS-Center for Medicare and Medicaid Services
COPM- *Canadian Occupational Performance Measure*
CRD-Community Resource Developer
DD-developmental disabilities
DHHS-United States Department of Health and Human Services
DSM-IV-*Diagnostic and Statistical Manual of Mental Disorders, 4th edition*
FY-fiscal year
GIS-geographic information systems
HCBS- home- and community-based services
HPSA-health professions shortage areas
HRSA-Idaho Health Resources Services Administration
IBAPP-Idaho Bioterrorism Awareness and Preparedness Program
ICFsMR-Intermediate Care Facilities for the Mentally Retarded
ICHC-Idaho Community HealthCorps
IDHW-Idaho Department of Health and Welfare
IRH-Institute of Rural Health at Idaho State University
ISSH-Idaho State School and Hospital
ISU-Idaho State University
LSR-*Life Status Review*

MCS-Mental Component Summary of the SF-12 Health Survey
MR-mental retardation
NIAAA-National Institutes of Alcohol Abuse and Alcoholism
NIDRR-National Institute of Disabilities and Rehabilitation Research
OT-Occupational Therapy
PCS-personal care service
PPS-*Pragmatic Problem Solving*
PTSD-post traumatic stress syndrome
Real Choices-Real Choices Systems Change Project
RERC-Rehabilitation Engineering Research Center
SF-12 Health Survey
SFY-State Fiscal Year
SHN-State Hospital North
SHS-State Hospital South
SLES-*Stressful Life Experiences Screening*
SOCO Single Overriding Communication Objective
SSDI-Social Security Disability Income
SSI-Supplemental Security Income
STAI/STAI-C-*State Trait Anxiety Inventory*
TBI-traumatic brain injury
WAIS-III-*Wechsler Adult Intelligence Scale-3rd ed.*
WISC-III-*Wechsler Intelligence Scale for Children-3rd ed*
WRAT-3-*Wide Range Achievement Test*

LIST OF TABLES AND FIGURES

Tables

Figures