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"NIDRR Priority Writing, Peer Review, and Grantee Outputs: An Evaluation" [2011] [2]

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Appendices

- A. Grant Summaries (n=30)
- B. Rating Sheets/Questionnaires
 - 1. Process Evaluation Measures:
 - a. Questionnaire for NIDRR Stakeholders
 - b. Questionnaire for NIDRR Peer Reviewers
 - 2. Summative Evaluation Measures:
 - a. Grantee Invitation Letter
 - b. Informed Consent Form
 - c. Grantee Questionnaire
 - d. Review Procedures for Summative Evaluation
 - e. Rating Sheet of the Quality of the Outputs
- C. Acronyms
- D. Committee and Staff Biographical Sketches

DRAFT GRANT/OUTPUT SUMMARY

Appendix A

This appendix contains individual summaries of all of the grants that participated in the summative evaluation. Abstracts of the grants were adapted from the abstract in each grantee's Annual Performance Report (APR) or were adapted from abstracts contained in NIDRR's National Rehabilitation Information Center (NARIC) (Available at: <http://www.naric.com/research/>). The outputs that were reviewed by the committee are also briefly described under each grantee. These brief descriptions were developed from examining the outputs themselves and adapting information from the abstracts of the outputs. The table below indicates the page in Appendix A where each grant's summary and description of their outputs can be found.

Funding Mechanism/Grant	NIDRR Grant Number	Page Number
Burn Injury (MS-Burn):		
Burn Model Systems/Data Coordinating Center	A020402	3
North Texas Burn Rehabilitation Model System	A020104	6
Traumatic Brain Injury (MS-TBI):		
Mayo Clinic TBI Model System	A020507	9
Spaulding/Partners Traumatic Brain Injury Model	A020513	11

Determined NOT to be
National Security Classified Marking
By MB (NLGB) on 8/12/16

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Funding Mechanism/Grant	NIDRR Grant Number	Page Number
System at Harvard Medical School		
Spinal Cord Injury (MS-SCI):		
Northern New Jersey Spinal Cord Injury System	N000022	14
The Missouri Model Spinal Cord Injury System	N000012	17
Rehabilitation Research and Training Center (RRTC):		
Meeting The Nation's Need for Personal Assistance Services: Center for Personal Assistance Services	B031102	19
RRTC on Disability Demographics and Statistics	B031111	22
RRTC on SCI: Promoting Health & Preventing Complications through Exercise	B031114	26
Rehabilitation Engineering and Research Centers (RERC):		
Rehabilitation Engineering Research Center on Telerehabilitation	E040012	29
RERC on Universal Interface and Information Technology Access	E030012	33

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Funding Mechanism/Grant	NIDRR Grant Number	Page Number
Disability and Rehabilitation Research Projects (DRRP):		
The Effect of Scheduled Telephone Intervention Outcomes after TBI	A040004	38
Asset Accumulation and Tax Policy Project	A031732	40
Medicaid Quality Indicators for Individuals with Disabilities	A040016	43
Persons Aging with Hearing and Vision Loss	A020701	45
Field Initiated Projects (FIP):		
Efficacy of Pressure Garment Therapy After Burns	G050022	47
A longitudinal study for hospitalization, pressure ulcers, and subsequent injuries after spinal cord injuries	G050165	48
Black-White Disparities in Stroke Rehabilitation	G050153	50
Development of Intelligent Personal Activity Management and Prompting Applications for Individuals with Cognitive Disabilities	G050313	52
Driving after Stroke	G050134	54
Functional Effects of Bifocal Use: Implication for Falling Intervention	G050340	56
Inclusive Indoor Play	G040324	58
Interference in Hearing Aids from Digital Wireless	G050228	59

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Funding Mechanism/Grant	NIDRR Grant Number	Page Number
Telephones		
Motor Training and Assessment in Adults with Hemiplegic Cerebral Palsy	G050151	60
Using the USS EEOC Employment Discrimination charge Data System for Research and Dissemination	G040265	62
Small Business Innovation Research, Phase II (SBIR):		
Universal Access to Passenger Rail Cars	S050136	64
Web-enabled creation and distribution of audio Tactile maps	S060105	66
Switzer Fellowship:		
A Noninvasive Surface Electromyogram Decomposition Method and Its Application in Disability Rehabilitation	F070022	67
Demographic Soup: Disentangling the Conceptual, Political, and Methodological Dimensions of Disability Statistics	F060011	68
Physical and Social Environmental factors that Influence Health and Participation Outcomes for Chronically-ill Adults	F080014	70

1

2

DRAFT GRANT/OUTPUT SUMMARY

1 **Grant Title:** Burn Model Systems/Data Coordinating Center

3 **Grant Award Number:** H133A020402

5 **Grantee:** University of Colorado Denver, Colorado School of Public Health

7 **Grant Mechanism:** DRRP-MS-Burn

9 **Grant Start and End Dates:** October 1, 2002 to September 30, 2008

11 **Total Direct Cost:** \$1,410,621

13 **Abstract¹:** The mission of the Burn Model System/Data Coordinating Center (BMS/DCC) was
14 to support the four burn model system clinical centers through: 1) serving the clinical, research,
15 and public communities to which it is responsible; 2) serving the needs of good scientific
16 procedure in multi-institutional outcomes research; and 3) supporting the needs for patient safety
17 and data confidentiality as required by federal regulations when conducting collaborative clinical
18 studies. To accomplish these objectives, researchers developed integrated systems to affect
19 national data collection, project management, data coordination, technical support, collaborative
20 clinical projects, scientific conduct, scientific publication, and effective dissemination.

22 A central function of the BMS/DCC was also to accumulate and integrate a central repository of

¹ Abstracts are adapted from the abstract in each grantee's APR, except for two which are marked with separate footnotes.

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data from the four burn model system clinical centers, while also being responsive to technical and analytical needs of the centers.

Research Projects and Outputs Reviewed: Annual Performance Report databases that were provided to NRC and which date back to FY 2006-2007 identified three outputs produced by this grant, three journal articles. In addition the grantee reported nine outputs, three journal articles, one technical report, one fact sheet, one website, and one data dictionary.

The following table shows three projects that were carried out under the grant. The projects were aimed at most of NIDRR's key research domains. Project A was aimed at the key research domains health and function, employment, and participation and community living. Project B was aimed at the key research domain health and function. Project C was aimed at the key research domains health and function, employment and knowledge translation, including technology transfer. The table also lists the outputs that correspond to the projects and which were reviewed by the NRC Committee. These outputs were identified by the study's key personnel as those which would best reflect their grant's achievements.

Project	Output
A. Establish and Maintain BMS Database	A1. Lezotte, D. C. (2008). <i>Model System for Burn Injury Rehabilitation</i> <i>National Database Data Dictionary</i> (16) [Data file and code book]. Denver, CO: Colorado School of Public Health, University

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	of Colorado Denver.
B. Develop and Implement Support Systems	B1. Lezotte, D.C., and Sloan, R. (2004) <i>Process Review of Level I Data Center Activities For Burn Model System/Clinical Sites</i> . Unpublished manuscript, Department of Biostatistics and Informatics, University of Colorado Denver, Denver, Colorado.
	B2. Klein, M, Lezotte, D., Fauerbach, J., Herndon, D., Kowalske, K., Carrougner, G., deLateur, B., Holivanahalli, R., Esselman, P., SanAgustin, T., Engrav, L. 2007. The NIDRR Burn Model System Database: A Tool for the Multi-center Study of the Outcome of Burn Injury. <i>Journal of Burn Care & Rehabilitation</i> , 28(1):84-96.
	B3. Lezotte DC, Hills RA, Heltshe SL, Holavanahalli RK, Fauerbach JA, Blakeney P, Klein MB, Engrav LH. (2007). Assets and liabilities of the Burn Model System data model: a comparison with the National Burn Registry. <i>Archives of Physical Medicine and Rehabilitation</i> , 88(12) supplement 2: S7-S17
	B4. Lezotte, D. (2011). [BMS Publications with DCC PI Support]. Unpublished fact sheet.
	B5. Fauerbach, JA, Lezotte, DC, Blakney, P, Chromes, FG, deLateur, BJ, Goodwin, CW, Herndon, DN, Kowalske, K, Patterson, DR, Engrav, LH. 2005. Burden of Burn: Influence of Burn Size and Distress on recovery of Physical and Psychosocial Function. <i>Journal of Burn Care & Rehabilitation</i> , 26(1): 21-32.

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	B6. M. H. Serghiou, M. W. Rose; F. S. Pidcock; P. C. Esselman; L. H. Engrav; K. J. Kowalske; D. C. Lezotte. (2008.) The WeeFIM [R] instrument - A paediatric measure of functional independence to predict longitudinal recovery of paediatric burn patients. <i>Developmental Neurorehabilitation</i> , 11(1):39-50.
C. Implement a Dissemination Strategy for BMS	C1. Public and Secured BMS Website for Consumer Information, BMS-DCC.ucdenver.edu
	C2. Kaufman MS, Graham CC, Lezotte D, Fauerbach JA, Gabriel V, Engrav LH, Esselman P. (2007). Burns as a result of assault: associated risk factors, injury characteristics, and outcomes. <i>Journal of Burn Care & Research</i> , 28(1):21-28.

Brief Description of the Outputs:

The first output (A1) reviewed from the BMS database project was a data dictionary. The data dictionary identifies what kind of data to collect and provides a coding scheme for the data. Data that should be collected include protected health information, patient status, preburn information, parts of body burned, parts of body grafted, skin related problems, distress level, and scarring problems.

Six of the outputs (B1-B6) came from the support system project. The second output (B1) reviewed was a technical report which describes site visit reviews of Burn Model System/Clinical Sites. Sites visits were conducted to review data management operating procedures, review data security and privacy, seek feedback and recommendations for improving

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1 operations, and identify collaborative projects for which BMS/DCC could provide more support.
2 Through the site visits, researchers assessed the quality of the data coming in from each site and
3 documented effective site specific management techniques and practices so they could be shared
4 with other sites.

5
6 The third output (B2) was a journal article from a descriptive study of both the data quality and
7 structure of the Research Burn Model System Database after ten years of existence. Klein et al
8 noted that a total of 4600 patients had been entered into the database. Data on these patients was
9 collected during hospitalization as well as at 6, 12, and 24 months after discharge. The structure
10 of the database included sections on demographics, injury complications, patient disposition, and
11 functional and psychological surveys. Researchers concluded that the data and structure of the
12 database were both high quality, and the database was an important resource in supporting the
13 work of Burn Model Systems projects.

14
15 The fourth output (B3) was a journal article from a study comparing the Burn Model System
16 population with the patients in the National Burn Registry. Patients from both populations were
17 compared in terms of demographics and burn characteristics at discharge and over the course of
18 follow up. Populations were compared in total, and also broken down into groups with similar
19 burns. Researchers discovered only minor and insignificant demographic variation between the
20 Burn Model System and the National Burn Registry populations. Lezotte et al concluded that the
21 Burn Model System population is a representative sample so results of studies using Burn MS
22 data should be generalizable.

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1 The fifth output (B4) was a list of publications from Burn Model System centers that were
2 produced with support from the Data Coordinating Center. The list includes sixteen published
3 journal articles, one journal article that was submitted for publication, and one journal article that
4 was to be submitted for publication.

5
6 The sixth output (B5) was a journal article describing a longitudinal study on the influence of
7 physical and psychological burden on burn recovery. Participants included 162 adults with major
8 burns from three burn centers. Participants were compared by level of burden and against publish
9 normative data. Fauerbach et al discovered that physical recovery was significantly slower for
10 participants with either large physical or psychological burden. Additionally, psychosocial
11 recovery was also significantly slower for participants with large psychological burden.
12 Researchers conclude that, in addition to treating the burns, clinicians must address physical
13 and psychological burden in order to promote recovery.

14
15 The seventh output (B6) was a journal article from a study of the effectiveness of the WeeFIM in
16 measuring the impact of burn size on functional independence and time to recovery. Two-
17 hundred-forty-nine patients, ages 6 months to 16 years, participated in the two year study.
18 WeeFim measurements were taken at discharge, at 6 months, 1 year, and 2 years after burn
19 injury. Results indicated that the WeeFIM could accurately describe the relationship between
20 burn size, functional capacity, and recovery up to 24 months after burn. Serghiou et al believe
21 the tool should be used more widely to track recovery of burn victims.

22
23 The eighth output (C1) and ninth output (C2) come from project on implementing a
24 dissemination strategy. The eighth output (C1) was the website for the Burn Model Systems Data

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1 Coordination Center. The website includes information about the DCC participating institutions,
2 study group criteria, program priorities and policies, consumer products, special topics, and
3 related links. The website also has a search function. Through the website researchers can access
4 BMS Publications, Systematic Reviews, Consumer Information, News Letters, and Facts and
5 Figures, and can also contact and collaborate with DCC staff.

6
7 The ninth output (C2) was a journal article from a study comparing victims intentionally burned
8 due to assault with victims unintentionally burned due to accident. Participants included 80
9 intentionally burned victims and 1982 unintentionally burned victims. Kaufman et al discovered
10 that intentionally burned victims were more likely to be female, black, unemployed, had higher
11 rates of substance abuse, had larger burns, greater mortality rates, and greater psychological
12 distress. Researchers hope that understanding the characteristics of intentionally burned victims
13 will lead to better health and social services for this population.

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Grant Title: North Texas Burn Rehabilitation Model System

Grant Award Number: H133A020104

Grantee: UT Southwestern Medical Center at Dallas

Grant Mechanism: DRRP-MS-Burn

Grant Start and End Dates: October 1, 2002 to September 30, 2008

Total Direct Cost: \$1,190,475

Abstract: The North Texas Burn Rehabilitation Model System conducted 5 research projects:

1) Barriers to return to work following major burn injury, 2) Long term outcome following major burn injury, 3) Outcome following deep full thickness hand burns, 4) Burn associated neuropathy: Evolution over time, 5) The socioeconomic determinants of disability in individuals with burn injury. Each of these projects linked directly with several areas of the NIDDR long-range plan. The plan of operation included clearly defined objectives, responsibilities, and timelines for model system demonstration, research, and dissemination. Additionally, researchers sought to close the loop and reassess progress of each activity and create intervention plans as needed to assure they met the proposed priorities.

Research Projects and Outputs Reviewed: Annual Performance Report databases that were provided to NRC and which date back to FY 2006-2007 identified six outputs produced by this

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grant, five journal articles and one newsletter. In addition the grantee reported seven outputs, four journal articles, one seminar, one clinic, and one intervention program, to the NRC Committee.

The following table shows the six projects that were carried out under the grant. The six projects were aimed at most of NIDRR's key research domains. Project A was aimed at employment. Projects B, C, and D were aimed at health and function. Project E was aimed at participation and community living. Project F was aimed at demographics. The table also lists the outputs that correspond to the projects and which were reviewed by the NRC Committee. These outputs were identified by the study's key personnel as those which would best reflect their grant's achievements.

Project	Output
A. Barriers to Return to Work After Major Burn Injury - Collaborative	A1. Esselman PC, Askay SW, Carrougner GJ, Lezotte DC, Holavanahalli RK, Magyar-Russell G, et al. (2007). Barriers to return to work after burn injuries. Archives of Physical Medicine and Rehabilitation, 88(12):S50-S56.
B. Long Term Outcome of Major Burn Injuries	B1. The Challenge of Burn Care: How to Maximize Outcomes – A Seminar
	B2. Holavanahalli, Helm, and Kowalske. (2010). Long-Term Outcomes in Patients Surviving Large Burns: The Skin. Journal of Burn Care & Research, 31(4):631-639.
C. Outcome following Deep	C1. Schneider, et al. (2008). Contractures in Burn Injury Part II:

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Full Thickness Hand Burns - Collaborative	Investigating Joints of the Hand. Journal of Burn Care & Research, 29(4):606-613.
	C2. Holavanahalli, et al. (2007). Outcomes After Deep Full-Thickness Hand Burns. Archives of Physical Medicine and Rehabilitation, 88(12) Supplement 2:S30-S35.
D. Burn-Associated Neuropathy: Evolution Over Time	D1. Gabriel, et al. (2009). Assessment of Recovery from Burn Related Neuropathy by Electrodiagnostic Testing. Journal of Burn Care & Research, 30(4): 668-674.
E. The Socioeconomic Determinants of Disability in Individuals with Major Burn Injury	E1. ETMC Outreach Satellite Clinic
	Holavanahalli, R., Lara, C., Tollar, A., Stevens, C., Crump, D., Ellsworth, B., Hall, S., Borman P., Card, C., Garzon, C. and Leal, D. (2006, 2008, 2009). <i>SOAR Annual Report</i> . Unpublished manuscript, Department of Physical Medicine and Rehabilitation, UT Southwestern Medical Center at Dallas, Texas; Parkland Regional Burn Center, Parkland Health and Hospital System Dallas, Texas.
F. Contribution to a Longitudinal National	F1. Holavanahalli, et al. (2006). Profile of Patients Lost to Follow-Up in the Burn Injury Rehabilitation Model Systems' Longitudinal

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Database	Database. Journal of Burn Care & Research, 27(5):703-712.
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Brief Description of the Outputs:

The first output (A1) reviewed was a journal article concerning a study of barriers to returning to work following burn injuries. Esselman et al followed 154 individuals who were hospitalized and met the American Burn Association criteria for major burn injury. Participants were asked to identify perceived barriers to their returning to work. Physical and wound issues, working conditions such as temperature and safety, and psychosocial factors such as flashbacks and appearance concerns all presented barriers to the return to work. Researchers concluded that returning to work involves treatment of both physical and psychosocial factors.

The second output (B1), which was associated with the long term outcomes project, was a one day seminar held to, "address critical issues in the treatment of individuals with burn injuries, including physical, psychological, and social outcomes." The seminar included fourteen presentations and one panel discussion on topics such as the pathophysiology of burns, wound and skin care products, neurological complications, psychological effects, and community reintegration and return to work. The seminar was intended to present relevant principles and techniques that physicians and other health care professionals could use to provide outpatient wound and skin care and rehabilitation following acute burn injuries.

The third output (B2), also associated with the long term outcomes project, was a journal article describing a study of long-term residual skin problems in persons with severe burn injuries.

Holavanahalli, Helm, and Kowalske evaluated 98 individuals who had survived burns over 30%

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1 or more of their total body surface area. Study participants were asked to complete a Patient
2 Information Form, a Medical Problem Checklist, and underwent a comprehensive physical
3 examination. The researchers identified problems that persist many years following the burn
4 injury, such as sensory loss and itching; problems that tend to decrease over time, such as painful
5 scars and skin rash; and problems that tend to increase over time, such as cuts and tears in fragile
6 burns. Researchers concluded there is need of better long-term follow-up with survivors of large
7 burns.

8
9 The fourth output (C1) and fifth output (C2) come from the project on full thickness hand burns.
10 The fourth output (C1) was a journal article from a study of the incidence and severity of hand
11 contractures after burn injury. Data were collected over 10 years from 985 adult burn survivors.
12 Twenty-three percent of study patients developed at least one hand contracture. Schneider et al
13 were able to identify statistically significant predictors of both contracture development and
14 number of contractures. Given the significant impairment hand contractures represent,
15 researchers believe use of the identified predictors will significantly aid burn survivors.

16
17 The fifth output (C2) was a journal article about a descriptive study on measuring hand
18 performance after deep hand burns. Thirty-two burn survivors participated. Fifty percent of
19 participants had amputations, 40% had functional range of less than 180 degrees, and 22% had
20 injury to the tendons in the hand. Participants took the Jebsen-Taylor Hand Function Test
21 (JTHFT), and Michigan Hand Questionnaire (MHQ). Holavanahalli, et al. concluded that, while
22 deep full-thickness burns did comprise hand performance, the muscles were generally still intact
23 enough to perform a modified grasp. Training programs on this grasp could be developed to aid
24 burn survivors.

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1
2 The sixth output (D1) was a journal article concerning a study on “natural recovery from
3 burn-related peripheral neuropathies”. The article is related to the project on burn associated
4 neuropathy. Thirty-six participants with burn-related neuropathy, out of 370 screened burn
5 survivors, were repeatedly tested for improvement. Mean time between the tests was 169 days.
6 Gabriel et al found significant improvement between the initial and follow-up tests, suggesting
7 burn-related neuropathy will naturally heal. According to researchers, the prognosis for recovery
8 from burn-related neuropathy had not been adequately described in literature prior to this study.

9
10 The seventh output (E1) and eighth output (E2) come from the project on fsocioeconomic
11 determinants. The seventh output (E1) was a quarterly outreach satellite clinic at the East Texas
12 Medical Center (ETMC) in Tyler, Texas (100 miles east of Dallas). Between 2002 and 2007, an
13 average of 25 patients were cared for at the clinic each quarter. Clinic personnel include
14 NTBRMS burn surgeons, Physical Medicine and Rehabilitation physicians and research
15 personnel. In addition to receiving medical care, patients participate in NTBRMS research
16 studies and educational programs on various burn rehabilitation topics. The clinic enables
17 patients living in the area to receive medical care for their burn injuries closer to their homes.

18
19 The eighth output (E2) was an intervention program which provides peer support during
20 recovery to burn patients and their families. Volunteer burn survivors and family members are
21 trained in peer support. Each burn unit patient receives a visit at least once a week from a trained
22 volunteer. Many burn unit patients have reported that the opportunity to speak with a recovered
23 peer made them more optimistic about their own recovery.

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1 The ninth output (F1) was a journal article describing a study to identify common characteristics
2 between burn survivors lost to follow-up at 6, 12, or 24 months after injury. The data in this
3 article represented a contribution to the Burn Longitudinal National Database. Participants were
4 tracked over two years through the Burn Injury Rehabilitation Model Systems' database.
5 Holavanahalli et al. identified characteristics related to both increased and decreased likelihood
6 of attending follow-up sessions with physicians. Researchers believed these findings will lead to
7 strategies to reduce attrition in burn survivors. Researchers report this study is the first of its kind
8 for burn survivors.

9

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1 **Grant Title:** Mayo Clinic TBI Model System

3 **Grant Award Number:** H133A020507

5 **Grantee:** Rehabilitation Hospital of Indiana

7 **Grant Mechanism:** DRRP-MS-TBI

9 **Grant Start and End Dates:** October 1, 2002 to March 31, 2009

11 **Total Direct Cost:** \$1,402,265

13 **Abstract:** The Mayo Clinic TBI Model System (TBIMS) was focused on three local research
14 projects: (1) Decision-making and outcomes of inpatient and outpatient rehabilitation pathways;
15 (2) Very long term (5-15+ years post-injury) process and outcome for people with TBI identified
16 through the Rochester Epidemiology Project; (3) Telehealth-based (internet) cognitive
17 rehabilitation. These projects were developed with careful attention to sample size, rigorous
18 methodology, practical issues of data acquisition, and the needs and feedback from people with
19 TBI, their family and significant others (SO). The Mayo Clinic TBIMS also continued to
20 contribute substantially to the TBIMS National Database and was involved in other collaborative
21 projects using this database.

23 **Research Projects and Outputs Reviewed:** Annual Performance Report databases that were
24 provided to NRC and which date back to FY 2006-2007 identified fifteen outputs produced by

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1 this grant, eleven journal articles, one classification system, one inventory, one guide, and one
2 set of audiovisual materials. In addition the grantee reported three outputs, two journal articles,
3 and one curriculum, to the NRC Committee.

4
5 The following table shows the four projects that were carried out under the grant. The projects
6 were aimed at three of NIDRR's key research domains. Project A was aimed at health and
7 function. Projects B and D were aimed at participation and community living. Project C was
8 aimed at health and function and technology. The table also lists the outputs that correspond to
9 the projects and which were reviewed by the NRC Committee. These outputs were identified by
10 the study's key personnel as those which would best reflect their grant's achievements.

Project	Output
A. Factors and effects on outcome of clinical decision making in selecting rehabilitation pathways after traumatic brain injury	A1. Malec, et al. (2009). Injury severity and disability in the selection of next level of care following acute medical treatment for traumatic brain injury. <i>Brain Injury</i> , 23(1):22-29.
	A2. James Malec, et al. (2007). The Mayo Classification System for Traumatic Brain Injury Severity. <i>Journal of Neurotrauma</i> , 24(9):1417-1424.
B. Process and outcome of TBI in the very long term	B1. Allen W. Brown, et al. (2004). Long-term survival after traumatic brain injury: A population-based analysis. <i>NeuroRehabilitation</i> , 19(1):37-43.
	B2. Flaada, et al. (2007). Relative Risk of Mortality after Traumatic Brain Injury: A Population-Based Study of the Role of

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Project	Output
	Age and Injury Severity. Journal of Neurotrauma, 24(3):435-455.
C. The feasibility and efficacy of telehealth-based cognitive rehabilitation	C1. Bergquist, et al. (2008). Internet-based cognitive rehabilitation in individuals with acquired brain injury: A pilot feasibility study. Brain Injury, 22(11): 891-897.
D. Minnesota Advocacy Project	D1. Minnesota Advocacy Project Curriculum
	D2. Malec, Brown, and Moessner. (2010). Two new measures for assessing advocacy activities and perceived control after acquired brain injury. Disability and Rehabilitation, 32(1):33-40.

Brief Description of the Outputs:

The first output (A1) reviewed was a journal article from the decision making project on the relationship demographic factors, post-traumatic amnesia, and ability limitations have with clinical decisions following moderate to severe TBI. Participants included 159 individuals suffering from post-traumatic amnesia who were also rated for ability limitations. Malec et al discovered through analysis of their results that post-traumatic amnesia and certain ability limitations were associated with the decision to admit vs. discharge a patient in 93% of the sample. Age with the only demographic factor associated with the decision. Researchers believe that using a standardized measure of ability limitations, which they have developed, should lead to more consistency in decision making for patients with TBI.

The second output (A2) was a journal article, also from the decision making project, which discusses a test of The Mayo Classification System for Traumatic Brain Injury Severity. The

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1 Mayo System can classify TBI from consideration of a number of factors, and unlike other
2 systems is not dependent on one factor. Malec et al classified a sample of 1501 individuals with
3 history of TBI. Researchers concluded that the Mayo classification system was accurate and
4 superior to other single indicator systems, and could be used in both retrospective research and
5 for planning care.

6
7 The third output (B1) and the fourth output (B2) were from the TBI in the very long term project.
8 Both outputs are based on the same data source, medical records of a random sample (n= 7,175)
9 of Olmsted County, MN residents. The third output (B1) was a journal article describing a
10 population-based cohort study of 1,448 Olmsted County, MN residents who developed TBI from
11 1985 to 2000. Analysis of the case fatality rates showed: (1) mild TBI to be associated with a
12 small but significant long-term survival rate; (2) severe TBI to be associated with a very high
13 fatality rate but; (3) six-month survivors of severe TBI had long-term survival rates similar to
14 those with mild TBI. Brown et al believe the similarity between mild TBI and six-month
15 survivors of severe TBI is a new finding that could lead to new community services for TBI
16 survivors.

17
18 The fourth output (B2) was a journal article describing a study that tested whether observed
19 versus expected mortality of individuals with TBI differed by age. Flaada et al divided cases into
20 three age groups, pediatric (<16), adult (16-65), and elderly (>65) and compared observed and
21 expected 6-month and 10-year mortality rates for each age group. Researchers discovered that
22 within 6-months more individuals died from TBI than expected for all age groups, with the
23 elderly group showing the greatest difference and the pediatric group showing the smallest
24 difference. However, after 10 years observed mortality for the pediatric and elderly groups

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1 matched expected rates, but larger percentage of adults died than was expected. Researchers
2 believe their findings will help clinicians target and better care for the most vulnerable
3 populations suffering from TBI based on age.
4

5 The fifth output (C1), from the feasibility and efficacy project, was a journal article about a study
6 which assessed whether or not individuals with brain injury including memory impairment could
7 learn to use an Internet-based cognitive rehabilitation program. Ten participants were trained in
8 using an IM system and participated in weekly therapy sessions. Bergquist et al reported that
9 only two participants missed a few of the sessions. Researchers believe this finding demonstrates
10 that individuals with memory impairment can participate in telerehab.
11

12 The sixth output (D1) and seventh output (D2) were both outputs from the Minnesota Advocacy
13 Project.

14 The sixth output (D1) was a Curriculum for training individuals with TBI and their
15 families/significant others in three contiguous Midwest states in effective self and system
16 advocacy skills. The four sessions of the Curriculum included presentations on advocacy, lessons
17 in civics, presentations on community organizing, and a mock hearing during which participants
18 can practice applying what they have learned. Creators hope the Curriculum will lead to more
19 independence for individuals with TBI.
20

21 The seventh output (D2) was a journal article from a study which evaluated two questionnaires.
22 The Advocacy Activities Scale (AAS) and the Perceived Control Scale for brain injury (PCS-BI)
23 were mailed to individuals with acquired brain injury. Analysis of the responses revealed that
24 both the AAS and the PSC-BI showed satisfactory internal consistency and concurrent validity

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- 1 with other measures. Malec, Brown, and Moessner concluded that survey researchers should use
- 2 both the AAS and PCS-SI where appropriate.

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Grant Title: Spaulding/Partners Traumatic Brain Injury Model System at Harvard Medical School

Grant Award Number: H133A020513

Grantee: Spaulding Rehabilitation Hospital

Grant Mechanism: DRRP-MS-TBI

Grant Start and End Dates: October 1, 2002 to September 30, 2008

Total Direct Cost: \$1,410,621

Abstract: The Spaulding TBI Model System (TBIMS) provided a comprehensive spectrum of care for people with TBI through the collaborative efforts of three hospitals that are part of Partners Health Care System, Inc. and three organizations that operate a variety of postacute rehabilitation programs. Over the course of their grant, the Spaulding TBI Model System completed published articles on the ability of the size of cerebral structures associated with memory to predict the outcome among people with TBI who participate in a memory rehabilitation program, the association between diffusion tensor imaging (routinely done as part of the fMRI's) and memory, the ability of fMRI in brain areas other than the prospectively chosen regions of interest to predict outcome of the memory rehabilitation program, the effect of repeated presentation of words on brain activation on fMRI, test-retest reliability of the Virtual Planning Test (VIP), a database study on the use of the Glasgow Coma Scale for predicting

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outcome in people with severe TBI, families/caregivers emotional status and support systems, functional neuroimaging and cognitive rehabilitation for people with traumatic brain injury, and depression amongst outpatients with traumatic brain injury. The Spaulding TBIMS enrolled 16 subjects in the national database during the first 3 months of the reporting period.

Research Projects and Outputs Reviewed: Annual Performance Report databases that were provided to NRC and which date back to FY 2006-2007 identified ten outputs produced by this grant, seven journal articles, one diagnosis instrument, one field-tested product, and one newsletter. In addition the grantee reported three journal articles to the NRC Committee.

The following table shows five projects that were carried out under the grant. The projects were aimed at three of NIDRR's key research domains. Projects A, B, C, D, and E were aimed at the key research domain of health and function. Project F was aimed at the key research domains of health and function, employment, and demographics. The table also lists the outputs that correspond to the projects and which were reviewed by the NRC Committee. These outputs were identified by the study's key personnel as those which would best reflect their grant's achievements.

Project	Output
A. Regional cerebral activation on fMRI as a predictor of outcome following TBI	A1. Strangman, et al. (2008). Prediction of Memory Rehabilitation Outcomes in Traumatic Brain Injury by Using Functional Magnetic Resonance Imaging. Archives of Physical Medicine and Rehabilitation, 89(5):974-981.

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	A2. "The Newscaster", 2008 Edition
B. Test-retest reliability of the Virtual Planning Test (VIP): Subjects with brain injury	B1. O'Neil-Pirozzi, et al. (2010). Test-re-test reliability of the virtual planning test in individuals with traumatic brain injury. Brain Injury, 24(3):509-516.
C. Risk of progressive cognitive deterioration in aged survivors of moderate to severe brain injury: a collaborative national database project	C1. Marquez de la Plata, et al. (2008). Impact of Age on Long-Term Recovery From Traumatic Brain Injury. Archives of Physical Medicine and Rehabilitation, 89(5):896-903.
D. Family members' and survivors' emotional well being: a collaborative module project	D1. Kreutzer, et al. (2009). Caregivers' Well-Being After Traumatic Brain Injury: A Multicenter Prospective Investigation. Archives of Physical Medicine and Rehabilitation, 90(6):939-946.
E. Efficacy of a group memory intervention: a pilot study	E1. O'Neil-Pirozzi, et al. (2010). A Controlled Treatment Study of Internal Memory Strategies (I-MEMS) Following Traumatic Brain Injury. Journal of Head Trauma Rehabilitation, 25(1):43-51.
F. TBI Model Systems National Database	F1. Arango-Lasprilla, et al. (2008). Racial Differences in Employment Outcomes After Traumatic Brain Injury. Archives of Physical Medicine and Rehabilitation, 89(5):988-995.

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Brief Description of the Outputs:

The first output (A1) and the second output (A2) were both associated with the project on regional cerebral activation on fMRI as a predictor of outcome following TBI. The first output (A1) reviewed was a journal article from a study into whether functional magnetic resonance imaging (fMRI) can be used to predict rehabilitation outcomes for TBI. Participants included 54 individuals who had suffered from TBI for at least 1 year. While being scanned, participants performed a word memorization task. Through analysis, Strangman et al were able to connect the fMRI results with success in completing the word memorization task. Researchers believe further research will clarify the relationship and allow fMRI to be used as a predictor of outcomes.

The second output (A2) was a newsletter. The grantee developed and widely distributed an annual newsletter discussing their study progress and findings to date. The newsletter was intended to provide a general audience with information about TBI and about this center's work.

The third output (B1) was from the project on the Virtual Planning Test (VIP). The output was a journal article from a study of the, "test-re-test reliability of the Virtual Planning Test (VIP) for individuals with traumatic brain injury (TBI)". Participants included 75 individuals with TBI. Participants each took the VIP twice, with 6-8 weeks separating the tests. After analysis of the results, O'Neil-Pirozzi et al concluded that the VIP had moderate overall test-re-test reliability for individuals with TBI, with some elements of the test showing high reliability, but other elements of the test showing low reliability. Researchers state the VIP is now the first such test with demonstrated test-re-test reliability for persons with TBI.

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1
2 The fourth output (C1) was from the project on progressive cognitive deterioration. The output
3 was a journal article from a longitudinal cohort study concerned with whether functional decline
4 after TBI was more likely for older individuals. Participants included 428 individuals with TBI
5 enrolled in the Traumatic Brain Injury Model Systems national dataset. Participants were divided
6 into three age groups, youngest (16–26y), intermediate (27–39y), and oldest (≥ 40 y). Data from
7 the first five years after the injury were examined for each age group. Marquez de la Plata et al
8 discovered that the greatest improvement over the first 5 years occurred in the youngest group,
9 and the greatest decline over the first five years occurred in the oldest group. Researchers believe
10 these finding suggest changes in TBI treatment practice in older individuals with TBI.

11
12 The fifth output (D1) was from the project on emotional well being. The output was a journal
13 article from a study on emotional distress and life satisfaction in caregivers. Participants included
14 273 caregivers who took the Brief Symptom Inventory-18 Depression, Anxiety, and Somatic
15 dimensions. Kreutzer et al discovered that 1 in 5 caregivers showed significant depression,
16 anxiety, and/or somatic symptoms. Higher distress was associated with caring for individuals
17 with worse functional status, individuals needing more supervision, individuals who were less
18 satisfied with life, and those who used alcohol in excess. Researchers believe these findings
19 reinforce the need to support caregivers as well as patients.

20
21 The sixth output (E1) was from a pilot study on group memory intervention. The output was a
22 journal article from a study on the effects of a memory group intervention on persons with
23 traumatic brain injury. Participants included 94 adults with TBI and resulting memory
24 impairment at least 1 year post injury at the time of study. O'Neil-Pirozzi et al discovered that

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1 participation in the intervention did improve memory for those with mild, moderate and severe
2 TBI (though there was less improve in cases of severe TBI), and the improvement was
3 maintained 1 month after the intervention. Researchers believe further research can build off of
4 this finding to increase use of memory group intervention.

5
6 The seventh output (F1) is part of the Center's contribution to the TBI Model Systems National
7 Database. The output was a journal article from a retrospective study examining racial
8 differences in the employment and occupation of individuals with TBI 1 year after injury. Data
9 for this study was taken from Traumatic Brain Injury Model Systems national database on 3486
10 white individuals and 1791 minorities hospitalized with TBI between 1989 and 2005. Arango-
11 Lasprilla et al discovered that whites were 2.17 times more likely to be employed 1 year after
12 TBI than minorities, though race did not have an impact on occupation. Researchers believe this
13 finding suggests more assistance should be given to minorities seeking work after TBI.

DRAFT GRANT/OUTPUT SUMMARY

1 **Grant Title:** Northern New Jersey Spinal Cord Injury System

3 **Grant Award Number:** H133N000022

5 **Grantee:** KMRREC

7 **Grant Mechanism:** Model Systems

9 **Grant Start and End Date:** September 1, 2000 to August 31, 2007

11 **Total Direct Cost:** \$1,361,714

13 **Abstract:** The Northern New Jersey Spinal Cord Injury System (NNJSCIS) was established as a
14 Model SCI Center in 1990 by NIDRR and serves the Northern New Jersey catchment area, a
15 thirteen-county ethnically diverse region of 10.2 million persons. It is a cooperative effort of the
16 Kessler Medical Rehabilitation Research and Education Center (KMRREC), the University of
17 Medicine and Dentistry of New Jersey University Hospital, and Kessler Institute for
18 Rehabilitation (KIR). For the original funding cycle, the NNJSCI model system focused on 6
19 research projects and one demonstration project. The subsequent funding cycle focused on
20 dissemination efforts, validation of the consumer index of accessibility demonstration project,
21 and continued recruitment and data collection for the database.

23 The 6 research projects addressed one of the most common medical problems faced by persons
24 with SCI (urinary tract infections), common health issues among individuals with SCI (obesity

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and upper limb overuse), promotion of health and wellness in individuals with SCI (health literacy and the identification of health and psychosocial risk factors), and developed an instrument for assessing outcomes and care specified by the Consortium for Spinal Cord Medicine's clinical practice guidelines (which was used to collect data and determine the validity of these guidelines). The consumer accessibility demonstration project tested the feasibility of an innovative methodology to expand community access for individuals with SCI.

Research Projects and Outputs Reviewed: The Annual Performance Report databases that were provided to the NRC, which date back to FY 2006-2007, identified eighteen outputs produced by this grant, fourteen journal articles, one book chapter, two interventional protocols and one newsletter.

The following table shows the five projects that were carried out under the grant. The projects were aimed at three of NIDRR's key research domains. Projects A, B, C, and D were aimed at the health and function domain. The table also lists the outputs that correspond to the projects which were reviewed by the NRC Committee. These outputs were identified by the study's key personnel as those which best reflect their grant's achievements.

Project	Output
A. Health Promotion and Disease Prevention Among Individuals with SCI	A1. Diab and Johnston. (2004). Relationships between level of disability and receipt of preventive health services.

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Project	Output
	Archives of Physical Medicine and Rehabilitation, 85(5):749-757.
	A2. Johnston, M.V., et al. (2005). Preventive services and health behaviors among people with spinal cord injury. Journal of Spinal Cord Medicine, 28(1):43-54.
B. Health Literacy: Its Relationship to Educational Materials and to Health-Related Outcomes Among Individuals with SCI Living in the Community	B1. Johnston, Diab, Kim, and Kirshblum. (2005). Health literacy, morbidity, and quality of life among individuals with spinal cord injury. Journal of Spinal Cord Medicine, 28(3):230-40.
C. Empiric Antibiotic Treatment for Urinary Tract Infections in Persons with SCI	C1. Linsenmeyer and Oakley. (2003). Accuracy of individuals with spinal cord injury at predicting urinary tract infections based on their symptoms. Journal of Spinal Cord Medicine, 26(4):352-7.
	C2. Consortium for Spinal Cord Medicine. (2006). Bladder Management for Adults with Spinal Cord Injury: A Clinical Practice Guideline for Health-Care Providers. The Journal of Spinal Cord Medicine,

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Project	Output
	29(5):527-573.
D. Changes in Shoulder Pain Intensity During Upper Extremity Exercise in Individuals with Spinal Cord Injury	D1. Dyson-Hudson, Sisto, Bond, Emmons, and Kirshblum. (2007). Arm Crank Ergometry and Shoulder Pain in Persons with Spinal Cord Injury. Archives of Physical Medicine and Rehabilitation, 88(12):1727-1729.
	D2. Dyson-Hudson and Kirshblum. (2004). Shoulder pain in chronic spinal cord injury, Part I: Epidemiology, etiology, and pathomechanics. Journal of Spinal Cord Medicine, 27(1):4-17.
E. Studies based on data submitted to National SCI Statistical Center database	E1. Kirshblum, Millis, McKinley, and Tulskey. (2004). Late Neurologic Recovery After Traumatic Spinal Cord Injury. Archives of Physical Medicine and Rehabilitation, 85(11):1811-1817.
	E2. Cardenas, Hoffman, Kirshblum, and McKinley. (2004). Etiology and Incidence of Rehospitalization After Traumatic Spinal

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Project	Output
	Cord Injury: A Multicenter Analysis. Archives of Physical Medicine and Rehabilitation, 85(11):1757-1763.

Brief Description of the Outputs:

All outputs reviewed by the NRC were publications. The first two journal articles produced from the Health Promotion and Disease prevention project analyzed the receipt of preventative services among people with spinal cord injury. The Johnston et al. (2005) article documented receipt of understudied preventative services and health behaviors in SCI patients and compared them to the general population. Diab and Johnston (2004) examined the relationships between level of disability and receipt of certain preventative services. Surprisingly, although deficiencies in the provision of preventive services were found, they were similar to those in the general population. However, these deficiencies could be particularly problematic in SCI patients given the narrower margin of health. The severity of disabilities was found to be related to the receipt of certain preventative services but not necessarily in a simple or unidirectional way. Regardless of disability, receipt of a checkup was an important determinant of receipt of preventative health services. It was therefore recommended that preventive care needs and safety factors be routinely assessed and provided for people with SCI.

Under the health literacy project the third output reviewed was a journal article (B1) which aimed to describe levels of health literacy in SCI patients and to investigate the possible associations with morbidity, health-related quality of life, functional independence, community participation, and life satisfaction. In this study, only 14% of people with SCI were found to

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1 have limited health literacy. Health literacy was found to be independently related to physical
2 health morbidity, but associations with other outcomes were limited, intertwined with education,
3 and affected by severity of injury.

4
5 The outputs produced under the third project (Empiric Antibiotic treatment for Urinary Tract
6 Infections) address one of the most common medical problems faced by persons with SCI,
7 urinary tract infection. Linsenmeyer and Oakley (2003) described a study aimed at evaluating
8 the accuracy of a person with SCI in determining whether s/he had a UTI based on signs and
9 symptoms. It found that 39% of SCI patients were not accurate in predicting a UTI based on
10 signs and symptoms. This supports the importance of performing a urinalysis before prescribing
11 antibiotics for treatment, in addition to having high suspicion of other medical conditions. The
12 other output from this project was a set of published guidelines (C2) for health providers on
13 bladder management for adults with spinal cord injury. These were developed by the
14 Consortium of Spinal Cord Medicine, led by a steering committee made up of one representative
15 with clinical practice guideline experience from each of the consortium's 17 member
16 organizations.

17
18 The next two outputs were journal articles from another project focused on analyzing shoulder
19 pain in persons with spinal cord injury. Dyson Hudson et al. (2007) addressed whether a primary
20 fitness program for people with SCI, which used arm cycle ergometry, resulted in increased
21 shoulder pain. It found that shoulder pain did not increase in SCI subjects who use wheelchairs
22 that performed moderate intensity arm crank ergometry. Dyson-Hudson and Kirshblum (2004)
23 outlined the epidemiology, etiology, and pathomechanics of shoulder pain in persons with SCI in
24 order to aid in the evaluation, treatment, and prevention of this disorder.

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1
2 The final two outputs reviewed (E1 and E2) were journal articles produced as part of the project
3 to conduct studies based on the National SCI Statistical Center Database. The first journal article
4 presents and analyzes Model Spinal Cord Injury System (MSCIS) data on late neurologic
5 recovery after 1 year post SCI. It found a small degree of recovery after traumatic SCI. In
6 addition, late conversion from complete recovery to incomplete recovery occurred in 5.6% of
7 cases. This knowledge may be useful for future surgical and pharmacological intervention
8 studies aimed at enhancing recovery. The last journal article performed an analysis of cross-
9 sectional data to determine the frequency and reasons for rehospitalization in person with acute
10 SCI during follow up years. It also examined the association between rehospitalization and
11 demographics, injury severity, payer sources, length of stay, functional status at discharge, and
12 discharge residence. This information is important for the development of preventive strategies
13 and management for persons with SCI in reducing rehospitalizations.

DRAFT GRANT/OUTPUT SUMMARY

Grant Title: The Missouri Model Spinal Cord Injury System (MOMSCIS)

Grant Award Number: H133N000012

Grantee: University of Missouri

Grant Mechanism: Model Systems

Grant Start and End Date: October 1, 2000 to September 30, 2007

Total Direct Cost: \$1,504,487

Abstract: The primary MOMSCIS research study focused on the effect of a consumer-directed personal assistance services training intervention on consumer satisfaction, independent living, and community integration. The MOMSCIS study developed, implemented, and evaluated the in-person Individualized Management of Personal Assistant/Consumer Teams (IMPACT) workshop. The IMPACT workshop participants received information on preventing and treating secondary medical conditions, including pressure sores, urinary tract infections, bowel and bladder management, autonomic dysreflexia, pain management, chronic fatigue, and thermoregulation. The participants also received information on relationship issues, such as hiring and managing personal assistants, communication styles and strategies, assertiveness, and team building. The objectives of the study were 1) to determine the effect of the IMPACT workshop on consumer satisfaction, the incidence of secondary conditions, activity, and participation; 2) to determine the effect of the IMPACT workshop on personal assistants' job

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1 satisfaction, job stress, and attrition; and 3) to provide online resources to the disability
2 community, including an online personal assistant training manual for consumers and assistants,
3 and an online resources database. A total of 99 consumers and 98 assistants participated in this
4 study. Activity and participation were measured by the Participation Survey for persons with
5 Mobility Limitations (PARTS/M). To leverage NIDRR's previous investment in developing the
6 PARTS/M, we collaborated with Washington University and the University of Pittsburgh to
7 combine data to validate the PARTS/M among a large sample of persons with SCI. These data
8 will provide valuable information for future studies seeking to document changes in personal
9 independence and community integration.

10
11 In a secondary research project, surveys were sent to 16 Model Spinal Cord Injury System
12 centers to assess which centers, during rehabilitation admission, screen for total testosterone
13 level among men with SCI. A study was also conducted to document the prevalence of low
14 testosterone among men with spinal cord injury. The study included 100 men with SCI, and
15 found that the prevalence of low testosterone was high. Specifically, 75% of participants had low
16 testosterone levels (under 300 ng/dl). In addition, testosterone level was significantly associated
17 with age and years since injury and with medical variables, including AST, ALT, hemoglobin,
18 hematocrit, and albumin level.

19
20 **Research Projects and Outputs Reviewed:** The Annual Performance Report databases that
21 were provided to the NRC, which date back to FY 2006-2007, identified nine outputs produced
22 by this grant, nine journal articles.

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The following table shows the project that was carried out under the grant. The project was aimed at the health and function domain. The table also lists the outputs, two journal articles, that correspond to the projects, which were reviewed by the NRC Committee. These outputs were identified by the study's key personnel as those which best reflect their grant's achievements.

Project	Outputs
A. Individualized Management of Personal Assistant/Consumer Teams (IMPACT)	A1. Schopp, L.H., Clark, M.J., Hagglund, K.J., Stout, B.J., Gray, D.B. & Boninger, M.L. (2007). Life activities among individuals with spinal cord injury living in the community: perceived choice and perceived barriers. <i>Rehabilitation Psychology</i> , 52, 82-88.
	A2. Clark, M.J., Hagglund, K.J., Sherman, A.K. (2008). A longitudinal comparison of consumer-directed and agency-directed personal assistance service programs among persons with physical disabilities. <i>Disability and Rehabilitation</i> , 30(9):689-695.

Brief Description of the Outputs:

The first output reviewed was a journal article by Schopp and colleagues (2007) which aimed to explore perceived choice over life activities and perceived barriers to engaging in life activities

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1 by persons with SCI. In addition, it used an inferential approach to examine relationships among
2 personal assistance services like perceived choice, satisfaction, and barriers. In the results
3 approximately half of the participants reported little or no perceived choice with employment,
4 and the majority reported low satisfaction with choice with employment. High percentages of
5 persons experienced physical accessibility and transportation barriers to accessing employment.
6 Physical impairment, pain, and fatigue were also barriers. The article therefore suggested
7 improvements of workplace and transportation accessibility, increased vocational supports, and
8 interventions to decrease pain and fatigue to engage persons with SCI in life activities such as
9 employment.

10
11 The Clark et al. (2008) article performed a longitudinal comparison of outcomes for persons who
12 were enrolled in agency-directed personal assistance services (PAS) programs and changed to
13 consumer-directed PAS programs. In-home interviews from a convenience sample of
14 participants revealed more satisfaction and fewer unmet needs after receiving consumer-directed
15 PAS rather than agency-directed PAS. This suggests that consumer-directed PAS enhances
16 outcomes for many persons with disabilities.

DRAFT GRANT/OUTPUT SUMMARY

Grant Title: Meeting The Nation's Needs For Personal Assistance Services: Center For
Personal Assistance Services

Grant Award Number: H133B031102

Grantee: University of California San Francisco

Grant Mechanism: RRTC

Grant Start and End Dates: July 1, 2003 to June 30, 2009

Total Direct Cost: \$3,913,045

Abstract: The University of California San Francisco (UCSF) proposed to establish a
Rehabilitation Research and Training Center (RRTC) for personal assistance services (PAS).
They conducted 4 large research projects which studied: (1) the relationship between formal and
informal PAS and caregiving support, and the role of assistive technology (AT) in
complementing PAS; (2) home and community PAS, including state and federal policies and
programs, barriers and new models to eliminate barriers to formal and informal PAS, and best
practice models in states and in the home and community; (3) the PAS workforce and workforce
development that reflects geographic diversity and addresses PAS workforce recruitment,
retention, compensation and benefits; professional training, development and networking for
PAS providers; and crossover issues between disability and aging providers; and (4) workplace
PAS and models to eliminate barriers to formal and informal PAS and AT in the workplace and

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1 identify best practice models in the workplace. In addition, they provided training, dissemination,
2 and technical assistance relative to PAS. The faculty are among the nation's leading researchers
3 in disability and PAS, with over 15 years of research and policy experience, numerous academic
4 publications, a previous track record of NIDRR funding for a national center for disability
5 statistics, and teaching experience in disabilities studies. The Center collaborated with faculty
6 members at the University of Maryland, University of Michigan, and West Virginia University,
7 as well as with the Topeka Independent Living Resource Center, InfoUse, and Institute for the
8 Future of Aging Services. A Blue Ribbon Advisory Committee of PAS users, disability
9 advocates, business leaders, independent living center leaders, and academics provided guidance
10 to the project.

11
12 **Research Projects and Outputs Reviewed:** Annual Performance Report databases that were
13 provided to NRC and which date back to FY 2006-2007 identified thirty two outputs produced
14 by this grant, twenty eight journal articles, and three websites, and one fact sheet.

15
16 The following table shows the four projects that were carried out under the grant, which were
17 aimed at most of NIDRR's key research domains. Project A was aimed at health and function and
18 demographics. Project B was aimed at health and function and participation and community
19 living. Project C was aimed at employment and participation and community living. Project D
20 was aimed at employment. The table also lists the outputs that correspond to the projects and
21 which were reviewed by the NRC Committee. These outputs were identified by the study's key
22 personnel as those which would best reflect their grant's achievements.

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Project	Output
A. Conduct research on formal and informal PAS and caregiving support and the role of assistive technology and evaluate models to eliminate barriers	A1. LaPlante, M.P., Kaye, H.S. & Harrington, C. (2007). Estimating the Expense of a Mandatory Home and Community-Based Personal Assistance Services Benefit Under Medicaid. Journal of Aging and Social Policy, 19(3), 47-64
	A2. PAS Center website, www.pascenter.org (Specifically pages on disability statistics and HBCS waiver info)
B. Identify, develop, evaluate, and disseminate PAS in home and community based settings	B1. Kitchener, M., Ng, T., Miller, N., & Harrington, C. (2005). Medicaid Home and Community-Based Services: National Program Trends. Health Affairs, 24(1), 206-212.
	B2. Kaye, S.H., LaPlante, M.P., & Harrington, C. (2009). Do Noninstitutional Long-Term Care Services Reduce Medicaid Spending? Health Affairs, 28(1), 262-272.
C. Conduct research on the PAS workforce and workforce development	C1. Kaye, H.S., Chapman, S., Newcomer, R.J., & Harrington, C. (2006). The Personal Assistance Workforce: Trends in Supply and Demand. Health Affairs, 25(4), 1113-1120.
	C2. PHI State Chart Book on Wages for Personal and Home Care Aides, 1999-2006
D. Identify, develop, evaluate and disseminate best practices for PAS in the	D1. Stoddard, S. & Kraus, L. (2006). Arranging for personal assistance services and assistive technology at work. A report of the Rehabilitation Research and Training Center on Personal

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Project	Output
workplace to facilitate employment for individuals with disabilities	Assistance Services. Disability and Rehabilitation: Assistive Technology, 1(1-2), 89-95
	D2. JAN Personal Assistance Services in the Workplace Resource Document, http://www.jan.wvu.edu/media/pas.html

Brief Description of the Outputs:

The first two outputs were produced under a project focused on personal assistance services (PAS) support and technological support. LaPlante et al. (2007) provided an estimate of the expense of a mandatory PAS benefit under Medicaid for persons with low incomes, low assets, and significant disability. The resulting estimate was one-tenth that originally estimated by the Congressional Budget Office due to the fact that they did not restrict their estimate to persons with the required institutional level of need. The creation of mandatory PAS benefit was therefore shown to be a fiscally achievable policy strategy. The other output reviewed for this project (A2) was the website for the PAS Center, specifically the pages on disability statistics and HBCS waiver information. This website has hosted the only historical database on waiver programs (1992-2007) and personal care and home health services (1999-2007) that includes types and numbers of participants, service expenditures, and total expenditures. This waiver information has been used by CMS, MedStat, AARP, the National Council of State Legislators, the GAO, and other national and federal organizations to help describe the breadth and depth of Medicaid HCBS programs more fully.

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1 The next two outputs were journal articles from a project aimed to identify, develop, evaluate,
2 and disseminate PAS in home and community based settings. Kitchener et al. (2005) conducted
3 a descriptive analysis of the latest program trends in three Medicaid home and community-based
4 services (HCBS), waiver, home health, and state-plan personal care, and reported a national
5 survey of cost control policies used on waiver programs in 2002. It showed new information on
6 the growth of Medicaid HCBS over 1992-2001. Waivers represented the majority of total HCBS
7 spending. Wide variations in HCBS spending and access to services were found across state
8 with most states using cost controls and having limited numbers of waiver slots. The study
9 showed trends across states showing growth in access to services but still suggested that there
10 was a large unmet need for those wait-listed for services. Published in Health Affairs, this
11 articles publicized this information beyond the long term care audience to an audience of health
12 policy makers and state officials. Kaye et al. (2009) analyzed whether noninstitutional long-term
13 care services reduce Medicaid spending long-term. Analysis of state spending from 1995 to
14 2005 showed that for two distinct population groups receiving long-term care services, growth in
15 spending was greater for states offering limited noninstitutional services as opposed to those with
16 large, well-established noninstitutional programs. Therefore, although expansion of HCBS
17 causes a short-term increase in spending, it is followed by a reduction in institutional spending
18 and long-term costs.

19
20 Under the PAS workforce and workforce development project, the two outputs reviewed were a
21 journal article and chart book. Kaye et al. (2006) used data from two U.S. population federal
22 surveys to assess the size of the workforce providing paid PAS and the relative growth of that
23 workforce compared with the population needing such services. They found that the workforce
24 providing non-institutional personal assistance and home health services tripled between 1989

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1 and 2004, growing at a much faster rate than the population needing such services. Medicaid
2 spending for such services increased dramatically, but both workforce size and spending for
3 similar services in institutional settings remained relatively stable. The article also confirmed
4 earlier findings of low wage levels and contributed an additional comparison of wage growth
5 compared with other occupations. These low wage levels, scarce health benefits, and high job
6 turnover rates highlighted the need for attention to policy to ensure a stable and well-trained
7 workforce in PAS to meet the growing demand. A State Chart Book on Wages for Personal and
8 Home Care Aides (C2) provides information on the wages received by Personal and Home Care
9 Aides in all 50 states and the nation over a 7-year period.

10
11 The final two outputs reviewed were a journal article and resource document produced as part of
12 the project to identify, develop, evaluate, and disseminate best practices for PAS in the
13 workplace to facilitate employment for individuals with disabilities. Stoddard and Kraus (2006)
14 conducted structured phone interviews to learn about how workplace PAS and assistive
15 technology (AT) were arranged for in the workplace, and the issues that arose. Organizations
16 were shown to construct approaches that fit the needs, abilities, and constraints of each
17 organization. The interview respondents identified a number of practices that are succeeding
18 including: the establishment of policies arranging for PAS; centralization of accommodation
19 budgets to remove work unit disincentives; and providing a shared personal assistant for
20 interpreting or for task related and personal care tasks. The final output was the "PAS in the
21 Workplace" document (D2) (available online) produced to provide resources and information for
22 Job Accommodation Network (JAN) users, including employers, employees with disabilities,
23 people with disabilities attempting to secure PAS, and others on workplace PAS.

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1

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DRAFT GRANT/OUTPUT SUMMARY

1 **Grant Title:** RRTC on Disability Demographics and Statistics

3 **Grant Award Number:** H133B031111

5 **Grantee:** Cornell University

7 **Grant Mechanism:** RRTC

9 **Grant Start and End Dates:**

11 **Total Direct Cost:** \$3,607,885

13 **Abstract:** The Cornell StatsRRTC sought to bridge the divide between the sources of disability
14 data and the users of disability statistics. They conducted research exploring: (1) the reliability of
15 existing data sources and collection methods, and (2) the potential to improve current and future
16 data collection efforts. They also conducted a set of related applied activities including: (a)
17 utilizing existing data sources to provide a comprehensive and reliable set of statistics, (b)
18 increasing access to and understanding of how statistics can be effectively used to support
19 decision making, and (c) working with key organizations to determine their needs and help them
20 maximize the use of disability statistics in their ongoing efforts to improve the lives of people
21 with disabilities and their families. The deliverable, resources, and services developed by this
22 grant provide: (a) tests of key hypotheses regarding the demographics of disability, (b) Best
23 Practices Guide for Surveying People with Disabilities, (c) a set of User Guides to existing data
24 sources, (d) options for improvement in the "national disability data system" the extensive, but

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highly fragmented efforts of the federal government to collect disability data and produce disability statistics, (e) a comprehensive set of disability statistics, (f) Annual Disability Report Cards (also called the Annual Disability Status Reports), (g) comprehensive disability and demographic statistics, www.disabilitystatistics.org, (h), on-line user-directed Disability Statistics Templates, (i) a Disability Statistics Syllabus, reflecting an extensive training curriculum, (j) an On-Call Technical Assistance Service and a targeted On-Call Disability Statistics Estimation Service, (k) a set of trainings targeted on key audiences, and (l) a State-of-the-Science conference and an edited volume on the current status of the national disability data system, recent advances and high priority options for improvement.

Research Projects and Outputs Reviewed: Annual Performance Report databases that were provided to NRC and which date back to FY 2006-2007 identified fifteen outputs produced by this grant, three journal articles, two reports, one book, four Disability Status Reports, one user guide series, and two websites.

The following table shows the five projects that were carried out under the grant. All five projects were aimed at NIDRR's key research domain of demographics. The table also lists the outputs that correspond to the projects and which were reviewed by the NRC Committee. These outputs were identified by the study's key personnel as those which would best reflect their grant's achievements.

Project	Output
A. Analysis of Existing Data	A1. Disability Statistics User Guide Series

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	A2. Stapleton, D., Honeycutt, T., & Schechter, B. (2010). Closures are the tip of the iceberg: Exploring the variation in state vocational rehabilitation program exists after service receipt. <i>Journal of Vocational Rehabilitation</i>, 32(1):1-16.
B. Data Collection Methods	B1. Weathers, R.R. (2009). Chapter 2: The Disability Data Landscape. In. A.J. Houtenville, D.C. Stapleton, R.R. Weathers II, R.V. Burkhauser (Eds.), <i>Counting Working-Age People with Disabilities What Current Data Tell Us and Options for Improvement</i> (pp. 27-68). Kalamazoo, Michigan: W.E. Upjohn Institute for Employment Research. Stapleton, D.C., Wittenburg, D.C., and Thornton, C. (2009). Chapter 9: Program Participants. In. A.J. Houtenville, D.C. Stapleton, R.R. Weathers II, R.V. Burkhauser (Eds.), <i>Counting Working-Age People with Disabilities What Current Data Tell Us and Options for Improvement</i> (pp. 299-352). Kalamazoo, Michigan: W.E. Upjohn Institute for Employment Research. B2. Stapleton, D.C., Livermore, G.A., She, P. (2009). Chapter 11: Options for Improving Disability Data Collection. In. A.J. Houtenville, D.C. Stapleton, R.R. Weathers II, R.V. Burkhauser (Eds.), <i>Counting Working-Age People with Disabilities What Current Data Tell Us and Options for Improvement</i> (pp. 381-418). Kalamazoo, Michigan: W.E. Upjohn Institute for Employment

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	Research.
C. ICF	C1. Bruyère, S., VanLooy, S., & Peterson, D. (2005). The International Classification of Functioning, Disability and Health (ICF): Contemporary literature overview. <i>Rehabilitation Psychology</i> , 50(2):113-121.
	C2. Bruyère, S. (2005). Using the International Classification of Functioning, Disability, and Health (ICF) to promote employment and community integration in rehabilitation. <i>Rehabilitation Education</i> , 19(2&3), 105-117.
D. Resource Center	D1. 2008 Disability Status Reports
	D2. www.disabilitystatistics.org
E. Technical Assistance and Training	E1. InfoUse Community Planning Tool: Disabilityplanningdata.com
	E2. Master training Module

Brief Description of the Outputs:

The first output (A1) reviewed, from the project on analyzing existing data, was the Disability Statistics User Guide Series, a set of 9 documents focused on nationally representative survey or administrative data sources such as the American Community Survey (ACS), Current Population Survey (CPS), and Panel Study of Income Dynamics (PSID). The user guides allow researchers, analysts, and other users of disability statistics to access complex data in an effective and efficient manner. The content of each guide was developed by subject experts. Each guide

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1 contains background, methodology, and definitions as well as strengths, limitations, and
2 implications of the data. Each guide also provides extensive documentation of the original data
3 sources. The creators believe that such a useable and thorough resource on disability statistics
4 did not previously exist.

5
6 The second output (A2) reviewed, also from the project on analyzing existing data, was a journal
7 article from a study on vocational rehabilitation service receipt by individuals with disabilities by
8 demographic, educational, and disability type (mental, physical, or sensory) and across states.

9 The study combined data on vocational rehabilitation services from the RSA-911 public use file
10 for fiscal year 2007, with data on people with disabilities by state and demographic group from
11 the 2007 ACS Public Use Microdata Sample. Stapleton, Honeycutt, and Schechter, discovered a
12 national average of 1.3 out of every 100 working-age adults with a disability complete VR
13 services, with significant variation both by state, by demographics, and by disability type.

14 Researchers conclude the differences suggest that VR services benefit some groups in certain
15 areas of the country more than others.

16
17 The third output (B1) was related to the project Data Collection Methods. The output was two
18 chapters from the book *Counting Working-Age People with Disabilities: What Current Data Tell*
19 *Us and Options for Improvement*. The book describes the kinds of valuable information current
20 statistics and data on working-age people with disabilities can provide, areas in which current
21 statistics and data are lacking, and ways in which statistics and data can be improved. Chapter 2
22 provides a foundation for the book, including definitions of disability, descriptions of major
23 national surveys placed, and comparisons of prevalence estimates from these data sources.

24 Chapter 9 describes, "the available data and statistics on working-age people with disabilities

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1 who participate in major federal programs.” The authors summarize, compare, and integrate data
2 on participation from major federal surveys, administrative data and statistics from federal
3 agencies, and state-level participation statistics from employment service programs

4
5 The fourth output (B2), from the same project as B1, was Chapter 11, Options for Improving
6 Disability Data Collection from *Counting Working-Age People with Disabilities: What Current*
7 *Data Tell Us and Options for Improvement*. In Chapter 11, Stapleton, Livermore, and She
8 present major limitations of current national disability data and statistics system based on the
9 information contained in the book and additional interviews with producers and consumers of
10 disability statistics. Authors then present and discuss relatively inexpensive options for
11 improving the system, as well as recommendations for expansion of the system.

12
13 The fifth output (C1) and sixth output (C2) are from the project on the International
14 Classification of Functioning, Disability and Health. The fifth output (C1) was a journal article
15 reviewing the literature on the ICF produced in the three years following its endorsement by the
16 WHO. The review includes literature from the fields of rehabilitation, psychology, and health
17 and human services. Bruyère, VanLooy, and Peterson conclude that ICF is being applied in
18 many governmental, health care, and rehabilitation clinical and research settings in the US and
19 abroad, though ongoing work is still needed to further implement and support the ICF.

20
21 The sixth output (C2) was a journal article reviewing selected rehabilitation literature on
22 applications of the ICF to medical rehabilitation, employment, and community participation for
23 persons with disabilities. The article first describes the ICF and the need for a common
24 classification system to inform data gathering and policy. The article then seeks to demonstrate

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1 the ICF's potential as a common system through a review of literature describing ICF relevance
2 and application to rehabilitation and health care delivery practice. The article goes on state that
3 the ICF could also potentially improve rehabilitation counseling practice in the areas of
4 employment and environmental factors. Bruyère also suggests next steps for implementing and
5 integrating the ICF into rehabilitation service delivery, counselor education, and research.

6
7 The seventh output (D1) and eighth output (D2) were developed as part of the grant's Resource
8 Center. The seventh output (D1) was the 2008 Disability Status Reports. Fifty-three individual
9 reports are produced annually, including a national level report and reports on each state,
10 Washington D.C., and Puerto Rico. The reports are based on analysis of the U.S. Census
11 Bureau's American Community Survey (ACS) Public Use Microdata Sample (PUMS). The
12 reports provide a summary of the previous year's statistics on non-institutionalized people with
13 disabilities. The reports are written such that anyone will be able to understand and use the
14 statistics. They contain information on disability prevalence based on population size,
15 employment, earnings, and household income across demographic subpopulations..

16
17 The eighth output (D2) was the DisabilityStatistics.org website. This website is a single, user-
18 friendly, accessible resource for disability statistics from the three major nationally
19 representative surveys that include disability measures, the American Community Survey (ACS)
20 Public Use Microdata Sample (PUMS), The Decennial Census 2000 Census Bureau's detailed
21 disability data tables and the Current Population Survey (CPS). Data is available at the national,
22 state, county, congressional district, or metropolitan area level as well as for American Indian/
23 Alaskan Native/ Hawaiian Home Areas. The site provides statistics on disability prevalence,
24 employment, income, and poverty status by disability type and by demographic characteristic.

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1 The site includes an interactive search tool and technical assistance can be provided to users
2 experiencing problems.

3
4 The ninth output (E1) was the Disabilityplanningdata.com website. This output relates to the
5 project on Technical Assistance and Training. This website is a community planning tool which
6 provides information on the disability population to aid urban, community, and service planners
7 in making decisions that will affect or determine community access for people with disabilities.

8 The website provides housing tables, as well as population tables at the county level. The
9 information in the tables is combined data from several years of the American Community
10 Survey. The website also includes a Data Guide which describes the American Community
11 Survey, and other significant national surveys, and provides links to further information on the
12 surveys. Planners have generally used information such as age, gender and race or ethnicity in
13 planning, and this website allows them to also use information on disability.

14
15 The tenth output (E2) was a training module from the project on Technical Assistance and
16 Training. The module seeks to train researchers and students to 1) understand available, existing
17 data on people with disabilities, 2) understand, access, and utilize existing descriptive statistics,
18 3) identify instances in which descriptive statistics on disability can and should be meaningful
19 used, and 4) discuss and apply disability statistics using a personally relevant case study. The
20 first section of the module provides a definition of disability and description of how surveys
21 identify disability. The second section includes an overview of the four major national survey
22 disability data sources. The final section provides cases studies and examples in which trainees
23 can apply the information from the first two sections. The module was created to improve use of
24 data and statistics in research and practice.

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1
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Grant Title: RRTC on SCI: Promoting Health & Preventing Complications through Exercise

Grant Award Number: H133B031114

Grantee: National Rehabilitation Hospital/Medstar Research Institute

Grant Mechanism: RRTC

Grant Start and End Dates: December 1, 2003 to November 30, 2009

Total Direct Cost: \$3,607,885

Abstract: Persons with SCI have long been ranked at the lowest end of the physical activity spectrum. Studies published over the past decades have addressed the need for persons with SCI to adopt habitual exercise as part of a healthy lifestyle. Benefits of exercise for people with SCI mirror positive multi-system health benefits documented for those without paralysis. However, despite ample documentation of these benefits no current exercise guidelines for people with SCI exist. NIDRR's Long-Range Plan Priorities 1 and 2 and the NIH NCMRR Research Priorities focus specifically on the development of clinical guidelines to identify individuals at risk for secondary conditions and to involve consumers in exercise regimens to prevent secondary conditions.

In response to these priorities, this RRTC systematically and comprehensively addressed the role and impact of physical activity in the prevention of secondary conditions in people with SCI. The

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1 RRTC was a collaborative effort of clinical and disability researchers, SCI consumer
2 organizations, and independent living advocates. Consumers were involved in the planning,
3 implementation, analysis and dissemination of all research and training activities. We established
4 critical physiological responses to exercise in SCI and comprehensively examined CVD risk in
5 individuals with SCI applying accepted guidelines used in the able-bodied population (R1). In
6 Projects R2 through R4 we develop exercise formats specifically designed according to severity
7 of SCI and chronicity of SCI to address the prevention of and knowledge regarding osteoporosis
8 and other secondary conditions. In R5 we determined whether regular exercise is related to fewer
9 secondary conditions. These research findings fed into four training activities that included a
10 peer mentoring program for newly injured people with SCI (T1), a consumer-driven education
11 curriculum for physical therapy and medical students (T2), a state-of-science and training
12 conference (T3), and the development of a virtual resource network on exercise and prevention
13 (T4).

14
15 **Research Projects and Outputs Reviewed:** Annual Performance Report databases that were
16 provided to NRC and which date back to FY 2006-2007 identified thirty five outputs produced
17 by this grant, fourteen abstracts, fourteen journal articles, one book chapter, one diagnosis
18 instrument, two training manuals, one fact sheet, one educational aids, and one set of audiovisual
19 materials.

20
21 The following table shows the five projects that were carried out under the grant. All five
22 projects were aimed at NIDRR's key research domain health and function. Additionally, Projects
23 D and E are cross cutting with domain participation and community living. The table also lists
24 the outputs that correspond to the projects and which were reviewed by the NRC Committee.

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- 1 These outputs were identified by the study's key personnel as those which would best reflect
 2 their grant's achievements.

3

Project	Output
A. Cardiovascular disease risk stratification across injury levels after spinal cord injury: assessment of need for intervention and its predictors	A1. Groah SL, Nash MS, Ward EA, Libin A, Mendez AJ, Burns P, Elrod M, Hamm LF. (2010). Cardiometabolic risk in community-dwelling persons with chronic spinal cord injury. J Cardiopulmonary Rehab and Prevention
	A2. Cardiometabolic education package
B. Effect of an acute intensive exercise intervention on the prevention of bone mineral density loss in individuals with spinal cord injury	B1. Groah SL, Lichy A, Libin A, Ljungberg J. (2010). Intensive electrical stimulation attenuates femoral bone loss in acute spinal cord injury. Journal of Physical Medicine and Rehabilitation, 2(12):1080-1087.
	B2. Bone health and osteoporosis education package
C. Effect of robotic body-weight supported treadmill training on bone mineral density and selected secondary conditions in individuals with SCI	C1. Hidler J, Hamm LF, Lichy A, Groah SL. Automating activity-based interventions: the role of robotics. JRRD. 2008; 45(2).
	C2. Robotics package
D. Comparison of exercise	D1. Kroll, T., Kehn, M., Ho, P-S., Groah, SL. .The spinal cord

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training formats in individuals with spinal cord injury	injury Exercise Self-Efficacy Scale (ESES): development and psychometric properties. The International Journal of Behavioral Nutrition and Physical Activity. 2007; 4(34).
	D2. Exercise and self efficacy package
E. Exercise and secondary conditions: a national survey of individuals with spinal cord injury	E1. Kroll, T., Neri, M., Ho, P-S . Secondary conditions in spinal cord injury: Results from a prospective study. Disability and Rehabilitation.2007; 29(15):1229-37
	E2. State of Science Video package

Brief Description of the Outputs:

Each pair of outputs that correspond to each project include a journal article publication and a consumer education package.

The first two outputs correspond to the cardiovascular disease risk assessment project. Groah et al. (2010) described cardiometabolic risk factors and risk clustering in people with SCI. The study was a large-scale cross-sectional one that assessed 121 individuals with motor complete SCI, making it one of the largest non-veteran studies of this type. The scope of the cardiopulmonary assessments was also much broader than previously performed and reported in the literature. The study indicated that cardiometabolic risk clustering in people with SCI differed by degree of injury. A preponderance of overweight/obesity was found in the entire population with SCI. 10% of the population with SCI had moderate to high 10-year risk of myocardial infarction or death. The consumer cardiometabolic education package (A2) included a coronary heart disease and SCI fact sheet, research highlights on obesity and heart disease after SCI, and an obesity trends animation piece.

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1
2 The next two outputs correspond to the project focused on the effects of acute intensive exercise
3 interventions on the prevention of bone mineral density loss in persons with SCI. Groah et al.
4 (2010) described the effects of intensive electrical stimulation (ES) on femoral bone mineral
5 density loss in acute SCI. They found that an intensive lower extremity ES program may
6 attenuate bone mineral density loss after acute motor complete SCI, although it remained
7 unknown whether these benefits would be maintained in the long run. This study is one the the
8 few randomized control trials investigating bone health in people with acute SCI. The consumer
9 bone health and osteoporosis education package (B2) included an osteoporosis and SCI fact
10 sheet resulting from an abstract on interim findings on osteoporosis in SCI presented at the 2007
11 American Spinal Cord Injury Annual meeting (awarded 3rd best presentation), and also presented
12 at the 2007 International Functional Electronic Stimulation Society Annual meeting.

13
14 As part of the project focused on the effect of robotic body-weight supported treadmill training
15 on bone mineral density and select secondary conditions in individuals with SCI, Hidler et al.
16 (2008) reviewed the use of robotic devices in delivering intense, activity-based therapies which
17 could result in significant exercise benefits for people with SCI. In the manuscript, they also
18 presented preliminary data from studies investigating the metabolic and cardiac responses during
19 and after 6 months of lower-limb robotic training. The early evidence suggested that
20 interventions such as robotic-assisted gait training may improve gait as well as metabolic and
21 cardiovascular performance. The findings from this project did not result in a consumer
22 education package and rather the informational outputs targeted physicians and physical
23 therapists. The robotics package (C2) therefore consists of 2 posters, "Cardiac and Metabolic
24 Benefits of Robotic-Assisted Gait Training after Spinal Cord Injury" and "Assymetric Bone

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1 Mineral Density Loss in Ambulatory Individual with Spinal Cord Injury: A Case Report" invited
2 for presentation at the Annual Meeting of the American Spinal Cord Injury Association (ASIA)
3 in 2007 and the Annual Meeting of the American Academy of Physical Medicine and
4 Rehabilitation (AAPM&R) in 2010 respectively. Knowledge from this project, however, was
5 able to be incorporated into consumer materials, A2 and B2.

6
7 The journal article (D1) produced under the fourth project comparing exercise training formats in
8 individuals with SCI describes the development and psychometric properties of the Exercise
9 Self-Efficacy Scale (ESES), a major outcome of the RRTC. Self-efficacy has wide application
10 in studies on exercise and other health promotion activities. However, few efforts existed to
11 assess self-efficacy in people with SCI. The article's preliminary findings indicate that the ESES
12 is a reliable instrument with high internal consistency and scale integrity. Consumer materials
13 (D2) dealing with the prevention of secondary conditions through exercise and promotion of
14 healthy life styles incorporated knowledge resulting from the ESES scale development. The
15 materials provided for the output included the ESES questionnaire itself and a fact sheet on
16 exercise and SCI.

17 The final two outputs reviewed were produced as part of the project on exercise and secondary
18 conditions: a national survey of individuals with SCI. Kroll et al. (2007) presented findings of a
19 prospective longitudinal study to determine significant predictors of pressure ulcers and urinary
20 tract infections in adults with SCI over 2 years. The findings suggested that experience of a
21 pressure ulcer at Time 1 as well as not being married or cohabitating with a partner and lack of
22 access to primary care services are significantly associated with the occurrence of a pressure
23 ulcer at Time 2. People who reported previous UTI, greater functional limitations in activities of

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1 daily living, and did not engage in exercise had associations with UTI at Time 2. The State of
2 Science Conference and associated dissemination materials (E2) included multidisciplinary
3 speakers and panel participants interested in the health and well-being of persons with SCI and
4 on research focused on understanding the impact of exercise and physical activity on the
5 prevention of secondary conditions in people with SCI.

6

7

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1 **Grant Title:** Rehabilitation Engineering Research Center on Telerehabilitation

3 **Grant Award Number:** H133E040012

5 **Grantee:** University of Pittsburgh

7 **Grant Mechanism:** Rehabilitation Engineering Research Center

9 **Grant Start and End Date:** June 1, 2008 to May 31, 2009

11 **Total Direct Costs:** \$3,046,093

13 **Abstract:** The vision of this RERC is to serve people with disabilities by researching and
14 developing methods, systems, and technologies that support remote delivery of rehabilitation and
15 home health care services for individuals who have limited local access to comprehensive
16 medical rehabilitation outpatient and community-based services. Research and development
17 activities include:

19 (1) Telerehabilitation Infrastructure and Architecture: development of an informatics
20 infrastructure and architecture that builds on existing programs and technologies of the
21 University of Pittsburgh Medical Center's e-Health System, supports the RERC's research and
22 development activities, meets HIPAA requirements, provides a test-bed for third party
23 telerehabilitation applications, and can be used as a model for future telerehabilitation
24 infrastructure;

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(2) Telerehabilitation Clinical Assessment Modeling: development of a conceptual model for matching consumers with telerehabilitation technology. The model is user-oriented and driven by consumer experiences regarding satisfaction, simplicity, and reimbursability of telerehabilitation;

(3) Teleassessment for the Promotion of Communication Function in Children with Disabilities: development of a web-based teleassessment infrastructure that links therapists and child participants, allowing therapeutic content to be adapted to the child's individual progress and abilities;

(4) Remote Wheeled Mobility Assessment: determines if individuals with mobility impairments can obtain appropriate prescriptions for wheeled mobility devices through the use of a telerehabilitation system based upon information and telecommunications technologies;

(5) Behavioral Monitoring and Job Coaching in Vocational Rehabilitation: researches technologies to conduct remote delivery of rehabilitation services to individuals who have limited access to rehabilitation services that are necessary to participate in and achieve education and employment outcomes in their community; and

(6) Remote Accessibility Assessment of the Built Environment: determines the effectiveness of a remote accessibility assessment system in evaluating the built environment of wheeled mobility device users.

Research Projects and Outputs Reviewed: The Annual Performance Report databases that were provided to the NRC, which date back to FY 2006-2007, identified fifty eight outputs produced by this grant, six abstracts, two book chapters, five journal articles, thirty-six proceedings, one intervention protocol, two field tested products, one piece of software, one fact sheet, one training manual, one set of audiovisual materials, one e-journal, and one website.

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The following table shows the six projects that were carried out under the grant. The projects were aimed at three of NIDRR's key research domains. Projects A, C, D and E were aimed at health and function. Project B was aimed at participation and community living, and Project F was aimed at employment. The table also lists the outputs that correspond to the projects and which were reviewed by the NRC Committee. These outputs were identified by the study's key personnel as those which would best reflect their grant's achievements.

Project	Output
A. Evaluation of Remote Wheelchair Prescription	A1. Schein, R.M., Schmeler, M.R., Brienza, D., Saptono, A., Parmanto, B. (2008). Development of a Service Delivery Protocol Used for Remote Wheelchair Consultation via Telerehabilitation.

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Project	Output
	Telemedicine and e-Health, 14(9):932-938.
	A2. Schein, R.M., Schmeler, M.R., Holm, M.B., Saptono, A., Brienza, D. (2010.) Telerehabilitation Wheeled Mobility and Seating Assessments Compared With In Person. Archives of Physical Medicine and Rehabilitation, 91(6):874-878.
B. Remote Accessibility Assessment of the Built Environment for Individuals Who Use Wheeled Mobility Devices	B1. Kim, JB and Brienza, DM; Development of a remote accessibility assessment system through three-dimensional reconstruction technology. <i>Journal of Rehabilitation Research and Development</i> 2006; 43(2): 257-272.
	B2. Kim J. Brienza DM. Lynch RD. Cooper RA. Boninger ML. Effectiveness evaluation of a remote accessibility assessment system for wheelchair users using virtualized reality. Archives of Physical Medicine & Rehabilitation. 89(3):470-9, 2008 Mar.
C. Information Infrastructure and Architecture	C1. VISYTER: Versatile and Integrated System for Telerehabilitation
	C2. Telerehabilitation Portal
D. Development of a Model for Clinical Assessment and Use of Telerehabilitation Services	D1. M Pramuka, L van Roosmalen, Telerehabilitation Technologies: Accessibility and usability. International Journal of Telerehabilitation, Spring 2009. P25-36. http://telerehab.pitt.edu/ojs/index.php/Telerehab/
	D2. World Wide Rehab (Online Telerehab Resource Tool); http://136.142.148.104/fmi/iwp/res/iwp_auth.html

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Project	Output
E. Development and Implementation of a Teleassessment Architecture for the Promotion of Communication Function in Children with Disabilities	E1. Speech-Language Telerehabilitation based on Cosmobot System
	E2. Secure Store-and-forward protocol for Telemonitoring
F. Behavioral Assessment and Job Coaching	F1. Publication: McCue, M. Fairman, A and Pramuka, M. (2010). Enhancing Quality of Life Through Telerehabilitation. Physical Medicine Clinics of North America, 21(1), 195-205.
	F2. Publication: Schmeler, M. Schein, R. McCue, M. & Betts, K. (2009). Telerehabilitation Clinical and vocational applications for assistive technology: Research opportunities and challenges. <u>International Journal of Telerehabilitation</u> 1(1), 59-72.

Brief Description of the Outputs:

The first output (A1) and second output (A2) were both journal articles from the Evaluation of Remote Wheelchair Prescription project. In the first journal article (output A1), Schein et al described their development of a service delivery protocol that will involve connecting rural wheelchair users with urban specialists via telerehabilitation technology. A repeated measure study design will be used with pre and post scores of the Functioning Everyday with a Wheelchair (FEW) outcome measure tool. As many rural areas lack qualified specialists,

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1 researchers intend to launch the study at one initial site and then subsequently replicate the
2 findings at several additional sites.

3
4 The second output (A2) was a journal article from a comparative assessment of wheeled mobility
5 and seating assessments in person at a clinic versus via telerehabilitation. Schein et al used a
6 prospective, multicenter controlled nonrandomized design at five wheelchair clinics in Western
7 Pennsylvania. Participants included 50 individuals assessed at a clinic and 48 individuals
8 assessed remotely. The study used the Functioning Everyday with a Wheelchair (FEW) outcome
9 tool to gauge whether both sets of participants were assessed equally well. Results showed no
10 significant differences in the quality of the assessment, indicating that such assessments can be
11 adequately completed via telerehabilitation.

12
13 The third output (B1) and the fourth output (B2) were journal articles from the project on
14 assessing the built environment. In the third output (B1), Kim and Brienza describe an accuracy
15 assessment they performed of the ability of their Remote Accessibility Assessment System
16 (RAAS) to create a 3-D reconstruction of a wheelchair users' environment for a clinician. Kim
17 and Brienza analyzed, "the accuracy of dimensional measurements in a virtual environment and
18 a comparison of dimensional measurements from 3-D models created with four
19 cameras/settings." The assessment led Kim and Brienza to identify which digital camera and
20 software package available to consumers was capable of running the system. Using the camera
21 and software, researchers conduct a successful field test of the system.

22
23 The fourth output (B2) was a journal article by Kim et al from a study comparing assessment of
24 home environment based on the RAAS image reconstruction with assessments of home

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1 environment based on in-person inspection. The comparison was done in three different homes
2 of people who use wheeled mobility devices. For each home, assessments by each method were
3 performs by a different specialist. Results indicated that assessments of the three homes by the
4 two methods were in agreement 94% of the time. Kim et al believe these results demonstrate that
5 the system could provide adequate service to wheel chair users in remote areas.

6
7 The fifth output (C1) and the sixth output (C2) were telerehabilitation products from the
8 Information Infrastructure and Architecture project. The fifth output (C1), VISYTER, was a
9 software platform for developing various telerehabilitation applications. The system includes
10 high-quality videoconferencing, stimuli presentation, remote multiple camera control, remote
11 control of the display screen, an eye contact teleprompter, and access to electronic health
12 records. Since its development, the VISYTER system has been used to evaluate remote
13 wheelchair prescriptions, aid adult autistic assessments, and facilitate international physical
14 therapy teleconsultations

15
16 The sixth output (C2) was the Telerehabilitation Portal. The Portal supports telerehabilitation
17 services such as remote wheelchair assessment and remote assessment of built environments.
18 The Portal also assists the grantee research team in managing clinical workflow, and increases
19 their ability to collaborate.

20
21 The seventh output (D1) and the eighth output (D2) were associated with the project on model
22 clinical assessment and telerehab. The seventh output was a journal article by Pramuka and van
23 Roosmalen discussing the strengths and weakness of various telerehabilitation technologies. The
24 article highlights a conceptual framework that can be used to match telerehabilitation

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1 technologies, clinical applications, and user capabilities. The authors also suggest some methods
2 of using the technology to improve effectiveness telerehabilitation versus in-person
3 rehabilitation.

4
5 The eighth output (D2) was the online resource tool, World Wide Rehab. The tool is resource
6 database for information related to telerehabilitation services, such as technologies, disability
7 types, and population types. It contains over 800 resources (case studies, journal publications,
8 reports etc.) in the area of telerehabilitation, as well as a compilation of State (Medicaid) policies
9 and clinical licensure policies related to telerehabilitation. The tool is available for all to use and
10 users are able to new to or update the information in the database. Creators envision the World
11 Wide Rehab site resulting in better informed clinicians and better informed patients.

12
13 The ninth output (E1) and tenth output (E2) were pieces of netware created as part of the
14 teleassessment architecture project. The ninth output (E1) was a telerehabilitation system adapted
15 from an existing stand-alone speech therapy system called Cosmobot. Researchers were able to
16 add a secure, usable two-way telemonitoring system to Cosmobot, creating a more dynamic and
17 valuable telerehabilitation system. Researchers believe these efforts provide both an example of
18 and a methodology for converting existing stand alone systems rehabilitation systems into
19 telerehabilitation systems. Converting existing systems is potential more cost effective for both
20 clinicians and patients that developing and distributing brand new systems. The tenth output
21 reviewed by the NRC (E2) was store-and-forward telemonitoring protocol used in secure
22 telemonitoring systems such as output E1. The protocol was new technology developed by the
23 grantee that has wide applications as more telerehabilitation systems are developed.

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1 The eleventh output (F1) and twelfth output (F2) were journal articles from the job coaching
2 project. In output F1, McCue, Fairman, and Pramuka review the literature on the history of
3 telerehabilitation. The authors write that telerehabilitation is still a developing field, but the
4 evidence from the literature suggests that the expressed advantages of telerehabilitation, lowering
5 costs while increasing access and performing interventions in a patient's comfortable, natural
6 environment, are being seen in the results of the rehabilitation and the quality of life of the
7 patients. Researchers conclude that telerehabilitation has largely been successful over the time of
8 its existence, but improvements can still be made and further research is needed.

9
10 The twelfth output (F2) was a journal article in which Schmeler et al summarize the clinical and
11 vocation applications of telerehabilitation. As presented by the authors, these applications
12 include, "pressure ulcer prevention; virtual reality applications; speech-language pathology
13 applications; seating and wheeled mobility applications; vocational rehabilitation applications;
14 and cost-effectiveness." The authors also provide discussion of clinical and policy issues related
15 to telerehabilitation, and discussion of some of the external influences on telerehabilitation.

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1 **Grant Title:** RERC on Universal Interface and Information Technology Access

3 **Grant Award Number:** H133E030012

5 **Grantee:** University of Wisconsin-Madison, Trace Center

7 **Grant Mechanism:** Rehabilitation Engineering Research Center

9 **Grant Start and End Date:** October 1, 2003 to March 31, 2009

11 **Total Direct Cost:** \$3,685,031

13 **Abstract:** The focus of this RERC is on both access to information (e.g., content) in its various
14 forms, as well as access to interfaces used within content and by electronic technologies in
15 general. The research and development program is carefully designed to provide an interwoven
16 set of projects that together advance accessibility and usability in a fashion that takes into
17 account, and supports, the full range of access strategies used by manufacturers and people with
18 disabilities. These strategies range from enhancing the design of mainstream products so that
19 they can be used by individuals with different ability sets to enhancing the ability of users to deal
20 with the information and interfaces as they encounter them. The program will look at advances
21 that would have both short- and long-term outcomes related to assistive technologies (AT),
22 interoperability, and universal design. It also includes research that has the potential to
23 completely rewrite the basic precepts and approaches for accessibility and usability of
24 information and interface technologies by people with disabilities, and may even impact the

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1 definitions and concepts of assistive technology and universal design. Key to these projects is the
2 development of new models and approaches for characterization of the functional requirements
3 of current and future interfaces, and a better understanding of the type, diversity, and similarity
4 of functional limitations across etiologies and disabilities.

5
6 **Research Projects and Outputs Reviewed:** The Annual Performance Report databases that
7 were provided to the NRC, which date back to FY 2006-2007, identified twenty two outputs
8 produced by this grant. These included three proceedings, two technical reports, two journal
9 articles, one book chapter, two diagnostic instruments, one checklist, two miscellaneous tools,
10 two industry standards, one working prototype, one patent, one product transferred to industry,
11 three educational aids, and one website. In addition the grantee reported six outputs, three journal
12 articles, two technical reports, and one proceedings.

13
14 The following table shows the eight projects that were carried out under the grant. All of the
15 projects were aimed at cross-cutting domains. The projects crossed over the following outcome
16 arenas/domains: participation and community living, health and function, employment,
17 technology, and knowledge translation, including tech transfer. The table also lists the outputs
18 that correspond to the projects, which were reviewed by the NRC Committee. These outputs
19 were identified by the study's key personnel as those which best reflect their grant's
20 achievements.

Project	Output
A. Tools to Facilitate Built in Cross-Disability	A1. Accessible and Usable Design of

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Project	Output
Access	Information and Communication Technologies (publication)
	A2. EZ Access Techniques Package and Checklist (tool)
B. Tools for Incorporation of Interoperability Features in Mainstream Products	B1. Accessible design and testing in the application development process: Considerations for an integrated approach (publication)
	B2. ISO 24752-2008 5 Part Universal Remote Console Standard
C. Server-Assisted and Virtual AT	C1. Ubiquitous accessibility, common technology core, and micro assistive technology (publication)
D. Support of National and International Standards and Guidelines Efforts	D1. Web Content Accessibility Guidelines (WCAG) 2.0 (publication)
	D2. Photosensitive Epilepsy Evaluation Tool-

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Project	Output
	with live capture (PEAT) (technology)
	D3. HFES 200.2 Software Accessibility Guidelines / ISO 9241-171 Software Accessibility Standard (technology)
	D4. User Needs Summary (information)
	D5. Report to the Access Board: Refreshed accessibility standards and guidelines in telecommunications and electronic and information technology (publication)
E. Disability and Interface Characterization Study	E1. Irwin et al. Force and impulse production during the use of a touch screen by individuals with motor control disabilities. (publication)
	E2. Instrumentation to characterize performance during information technology use. (tool) (Force plate instrumentation to assess kinetic variables during touch screen use)
F. Abstract User Interfaces and Interface	F1. Trewin, et al. Abstract representations as a

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Project	Output
Sockets	basis for usable user interfaces. (publication)
	F2. Universal Remote Console (URC) Hub. (technology)
G. Technology Watch and State-of-the-Science Conference	G1. Over the horizon: Potential impact of emerging trends in information and communication technology on disability policy and practice. (publication)
	G2. Online Emerging Technology Overview. (information)
H. Direct Brain Interface Study	H1. Felton, et al. Brain-computer interface target acquisition tasks using Fitts' law. (publication)

Brief Description of the Outputs:

The first output (A1) and second output (A2) were both from the project on cross-disability access. The first output was a book chapter which describes the changing nature of accessible interfaces to information and communication technologies (ICT). The chapter includes discussion of assistive technology interfaces, pluggable user interfaces, universal design, and how the meaning of these terms has changed and continues to change. The chapter also includes discuss of future challenges and opportunities related to ICT interfaces.

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1
2 The second output (A2) was a tool. The EZ access Techniques Package and Checklist is a
3 “system of design techniques and hardware components” that are used in conjunction with
4 existing interactive electronic products to make the products more usable and accessible. EZ
5 Access does require a functional level of sight or hearing and the ability to press a button or use a
6 touchscreen. However, EZ Access has been shown to increase access for many individuals with a
7 single severe disability, and for some with combinations of disabilities. According to creators,
8 prior to development of EZ Access there were no cross-disability interface assistance tools
9 available to the general public.
10

11 The third output (B1) and fourth output (B2) were both from the Tools for Incorporation of
12 Interoperability Features in Mainstream Products project. The third output (B1) was a journal
13 article on an integrated approach to accessible design. Zimmermann and Vanderheiden believe
14 accessible design principles should be applied through any product development cycle. They
15 suggest using “personas” to model the user base and derive design guidelines which will form
16 the basis of the accessibility evaluation. From this point, iterative testing can be used to finalize
17 the design. These principles are all in agreement with existing best practices of software
18 engineering.
19

20 The fourth output (B2) was a five-part ISO standard for Universal Remote Consoles. The five
21 parts include Framework, User Interface Socket Description, Presentation Template, Target
22 Description, and Resource Description. The standard is intended for industry developers and
23 manufacturers of electronic information and communication products and systems. The standard
24 directs network technology product design to expose an “interface socket” which will allow

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1 users to control the new products with a previously existing interface. Products created according
2 to the standard will allow users with disability access through this “interface socket” using their
3 own interface. Creators believe the ability to use a known interface will allow users with
4 disability access to more products.

5
6 The fifth output (C1) was a journal article associated with the project, Server-Assisted and
7 Virtual AT. The article is a commentary by Vanderheiden on changes in accessibility to
8 computing since publication of a landmark Glinert and York article in 1992. Changes include
9 awareness of the need to design for accessibility, and increased and improved accessibility
10 features built into every operating system. Areas that have not changed included the prohibitive
11 cost and limited availability of assistive technologies and the lag between new technology and
12 necessary accessibility features. Vanderheiden believes researchers should be exploring new
13 concepts to further improve assistive technologies, such as, “a common technical core,
14 ubiquitous accessibility, micro assistive technology, and free public accessibility.”

15
16 The sixth output (D1), seventh output (D2), eighth output (D3), ninth output (D4), and tenth
17 output (D5) were all developed under the project on standards and guidelines. The sixth output
18 (D1) is a set of guidelines on web content accessibility. The guidelines cover methods for
19 making content accessibility to people with disabilities such as, “blindness and low vision,
20 deafness and hearing loss, learning disabilities, cognitive limitations, limited movement, speech
21 disabilities, photosensitivity and combinations of these.”

22
23 The seventh output (D2) was a diagnostic instrument. The Photosensitive Epilepsy Analysis Tool
24 (PEAT) captures a video of a website in action and then analyzes the video for website content

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1 that may induce seizures in people with photosensitive seizure disorders. The analysis includes
2 the details of the severity of the risk associated with content, and suggestions for modifications
3 that could remove the risk. PEAT is a free, downloadable resource for web developers.
4

5 The eighth output (D3) was a set software accessibility standards. The HFES Guidelines is the
6 American standard, and the ISO is the European standard. The purpose of each standard is to
7 provide guidance for designing accessibility into human-system software interfaces. Over time,
8 American and European standards and guidelines had diverged. This effort created two new,
9 harmonized standards. Creators believe the harmonized standards will result in superior
10 technology overall and will foster international collaboration.
11

12 The ninth output (D4) was a technical report on the user needs of people with disabilities. The
13 report is intended for standards developers, developers of information technology products, and
14 accessibility advocates. The report describes the needs of users with a wide range of disabilities,
15 identifies the common problems these users face when interfacing with technologies, and can be
16 used to analyze whether or not accessibility measures will be effective.
17

18 The tenth output (D5) was a technical report containing recommended standards and guidelines
19 for updating regulations that implement two laws regarding accessible information and
20 communication technology, Section 508 of the Rehabilitation Act and Section 255 of the
21 Communications Act of 1996. These two laws represent the core of all of the U.S. accessibility
22 policy regarding information and communication technologies. The recommended updates will
23 create guidelines which will work better across all technologies and devices, are agile enough to

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1 provide guidance for technology that will be created in the near future, and are also more in line
2 with international standards.

3
4 The eleventh output (E1) and the twelfth output (E2) were created during the Disability and
5 Interface Characterization Study. The eleventh output (E1) was a journal article touch screen use
6 by individuals with motor control disabilities. Irwin et al, citing a lack of such research,
7 examined how well participants with Cerebral Palsy and Multiple Sclerosis were able to use a
8 touch screen. Kinetic variables and dwell time were measured. Researchers determined that
9 button size may be the key variable to allow users with motor control disabilities to more easily
10 use devices with touch screens.

11
12 The twelfth output (E2) was a proceedings article on the development of instrumentation to
13 measure the force applied to a touch screen. Irwin et al designed touch screen force plate to
14 measure force applied by different users to a touch screen. They conducted a pilot study of the
15 force plate with participants including individuals with motor control disabilities and non-
16 disabled participants. Results from the pilot indicated the plate was successfully able to measure
17 force for all users. Researchers believe the instrumentation is the first of its kind. The force plate
18 was used by researchers in study described in output E1.

19
20 The thirteenth output (F1) and the fourteenth output (F2) were associated with the project on user
21 interfaces. The thirteenth output (F1) was a journal article which examined four standards for
22 abstract description of user interfaces. Trewin, Zimmermann, and Vanderheiden describe a
23 'universal remote console' scenario in which a personal device could easily connect and operate
24 any other local relevant device or service. Authors also identify two research challenges related

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1 to tagging and authoring. Researchers conclude that the technologies XForms and URC posses
2 the most potential to support a universal remote console scenario.

3
4 The fourteenth output (F2) was a piece of technology, the Universal Remote Console Hub. The
5 Hub accesses the user interface of multiple electronic devices and then provides access to all of
6 them through one interface. Creators believe the Hub simplifies access to multiple devices and
7 allows multiple devices to be controlled simultaneously. The Hub is intended to greatly improve
8 access for persons with disabilities through the creation of one easy to use interface that can
9 operate many devices.

10
11 The fifteenth output (G1) and the sixteenth output (G2) were associated with the grant's State of
12 the Science Conference. The fifteenth output (G1) is a technical report that provided an overview
13 and analysis of the trends in technology and their impact and potential impact on various
14 dimensions of accessibility and disability policy. The report includes such topics as trends and
15 technological advances that are changing the rules, new opportunities, barriers, concerns, and
16 seven general recommended actions to be taken on an R&D and policy basis.

17
18 The sixteenth output (G2) was a website. The Emerging Technology Overview website is an
19 online review put together in 2007 of selected emerging information and communications
20 technologies. The website presents the information as a series of slides with images and links to
21 further information. The intent of the website is to provide a sense of how future ICT could
22 impact disability access. Technology noted in the Overview was selected to illustrate significant
23 changes. The Overview was not intended to be exhaustive and has not been updated since its

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1 posting. It was the hope of the creators that this website would promote awareness of the issues
2 related to information technology and the needs of users with disabilities.

3
4 The seventeenth output (H1), produced for the Direct Brain Interface Study, was a journal
5 article. Felton et al explored whether Fitts' law applies when non-disabled and disabled
6 individuals are moving a cursor on a computer screen through neural signals. Participants
7 included 8 non-disabled and 5 motor disabled participants who moved a cursor on a computer
8 screen through use of an EEG. Comparisons were made between non-disabled and disabled
9 participants, and between EEG and joystick cursor movement in non-disabled participants.
10 Analysis of the results should that Fitts' law did apply to the cursor movement by neural signals
11 by both the non-disabled and disabled participants. Researchers believe this work has
12 implications for future design of devices controlled by neural signals.

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1 **Grant Title:** The Effect of Scheduled Telephone Intervention on Outcomes after TBI

3 **Grantee:** University of Washington

5 **Grant Award Number:** H133A040004

7 **Grant Mechanism:** Disability and Rehabilitation Research Projects

9 **Grant Start and End Dates:** June 1, 2005 to May 31, 2010

11 **Total Direct Cost:** \$3 million

13 **Abstract:** About 80,000 survivors of TBI are discharged from the hospital with long-term
14 disabilities. Few interventions for persons with moderate to severe TBI have been shown to
15 improve outcome. We carried out a randomized controlled trial in three widely disparate sites
16 (Seattle, WA, Philadelphia, PA, and Jackson, MS) to examine the effect of scheduled telephone
17 intervention (STI) for persons with TBI after discharge from the hospital on function and quality
18 of life at one and two years. Specific Aim 1 evaluated the effect of STI at weeks 1-2, 4, 8 and 12
19 and months 5, 7, and 9 on functional level, health and emotional status, community integration
20 and perceived quality of well being over one year after TBI. Specific Aim 2 evaluated the effect
21 of additional STI at months 15, 18, and 21 on the same variables and employment at two years
22 after TBI. Specific Aim 3 evaluated whether the effects of such an intervention are similar in
23 multiple sites over a wide geographic area and in demographic subgroups. Specific Aim 4
24 examined the differential impact of the intervention in demographic subgroups, with particular

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1 attention to minority versus non-minority racial and ethnic populations.

2
3 This project examined the effect of a low-cost, easily implemented intervention on functional
4 and health outcomes. The study randomized survivors of TBI on discharge from inpatient
5 rehabilitation. Both groups received the usual care. The experimental group also received STI.

6 This study was based on a successful pilot single-site study carried out at the principal site
7 (Seattle). This extension allowed cross-validation of the original results and determined whether
8 the treatment and its results could be generalized to other disparate sites. Additionally,
9 continuing STI through the second year allowed meaningful evaluation of effect on return to
10 work. Timely intervention to identify problems after TBI, to teach patients and their families
11 coping techniques within their own communities and support their independent decision-making
12 effectively decreased the need for expensive and usually inaccessible services and improved the
13 quality of life for survivors of TBI. A successful multi-center demonstration of this technique has
14 convincing implications for health care policy and provision of services to persons with TBI.

15
16 In addition to our original purpose, we carried out a validation study of the Community
17 Participation Indicators, a measure being developed by Heinemann under NIDRR auspices. We
18 compared responses from persons with TBI with those from participant-identified significant
19 others to determine the validation of proxy responses for this instrument.

20
21 **Research Projects and Outputs Reviewed:** Annual Performance Report databases that were
22 provided to NRC and which date back to FY 2006-2007 identified one output produced by this
23 grant, one journal article. In addition, the grantee reported one workshop to the NRC Committee.

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The following table shows the project that was carried out under the grant, which was aimed at NIDRR's key research domain of health and function. The table also lists the outputs that correspond to the project and which were reviewed by the NRC Committee. These outputs were identified by the study's key personnel as those which would best reflect their grant's achievements.

Project	Output
A. The Effect of Scheduled Telephone Counseling on Outcome after TBI	A1. Participant-Proxy Agreement on Objective and Subjective Aspects of Societal Participation Following Traumatic Brain Injury. J Head Trauma Rehabil, 2010 Sep-Oct;25(5):339-48.
	A2. Workshop at American Congress of Rehabilitation Medicine: An Experience-Based Discussion of Challenges to Conducting Multicenter Clinical Trials in Rehabilitation

Brief Description of the Outputs:

This DRRP did not find a significant difference between treatment groups receiving scheduled telephone interventions and control groups. Secondary analyses were planned to see whether any subgroups within the intervention group had a differential response and any potential effects of intervention dosage. The intervention did not achieve its goals as it was applied in the study. As such, the outputs reviewed by the NRC address some of the challenges and lessons learned on carrying out the study.

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1 The first output (A1) is a journal article examining participant and proxy (significant other)
2 agreement when reporting societal participation in 3 objective domains (economic, community,
3 and social activities) and subjective satisfaction with participation at 1 year after traumatic brain
4 injury. It found that proxy report may be an acceptable substitute for missing participant report
5 on productivity and community activity outcomes, but should be used with caution for questions
6 about social activities and degree of satisfaction with participation.

7
8 The second output (A2) was a workshop at the American Congress of Rehabilitation Medicine,
9 An Experience-Based Discussion of Challenges to Conducting Multicenter Clinical Trials in
10 Rehabilitation. The day-long workshop proposed to analyze the project for what experimental
11 factors may have contributed to its unexpected outcome. This included factors in framing the
12 research question, the use of pilot data, study design, recruitment and consenting of subjects,
13 protocol management and treatment fidelity, data collection and quality monitoring, data
14 analysis, effective dissemination, grant management, and IRB concerns.

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1 **Grant Title:** Asset Accumulation and Tax Policy Project

3 **Grant Award Number:** H133A031732

5 **Grantee:** University of Iowa

7 **Grant Mechanism:** Disability and Rehabilitation Research Projects

9 **Grant Start and End Date:** June 1, 2007 to April 9, 2009

11 **Total Direct Cost:** \$1,438,795

13 **Abstract:** The proposed AATPP adopted a team-based participatory approach to research,
14 training, education, and technical assistance activities to bring to bear expertise in multiple
15 disciplines: law, economics, community development, finance, disability studies, and public
16 policy--with real-world experience of persons with disabilities and their families, financial
17 service providers, and community developers. Over a five-year period, LHPDC and its strategic
18 partners systematically examined the relation between tax policy and asset accumulation for
19 persons with disabilities, and resultant improvements in economic and community integration.
20 The AATPP investigated the impact of multiple intervention strategies--including financial
21 education, matched savings accounts, expanded financial services, and increased use of state and
22 federal tax incentives for asset and community economic development--in six states and ten pilot
23 demonstration sites nationwide on youth in transition and adults with disabilities. The AATPP's
24 research design used triangulated quantitative and qualitative techniques and a multi-method

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design (e.g., structured and open-ended interviews, archival analyses, policy and systems analysis, and survey techniques) to enhance the scientific rigor, policy relevance, and real-world usefulness of the research to key stakeholders, including persons with disabilities, policymakers, financial service providers, and community-based organizations.

The AATPP's knowledge transfer activities included twelve complementary methods for reaching target audiences through avenues such as publications, electronic communication, trainings, open forums, leadership institutes, and technical assistance activities. The project partners' dissemination networks extended to all fifty states in the disability community and the asset accumulation and community development sectors. The project collaborators brought a unique combination of expertise and experience as researchers, policy analysts, and practitioners in asset development (at an individual and systems level) and economic development (at a local and state levels) to enhance knowledge transfer and impact nationwide.

Research Projects and Outputs Reviewed: The Annual Performance Report databases that were provided to the NRC, which date back to FY 2006-2007, identified sixteen outputs produced by this grant, three journal articles, two technical reports, one book, one web journal, one intervention protocol, one tour, one online distance education series, one industry standard, one piece of software, two training manuals, and two newsletters.

The following table shows the four projects that were carried out under the grant. The projects were aimed at three of NIDRR's key research domains. Project A was aimed at the participation and community living domain; project B was aimed at cross-cutting domains. Projects C and D were aimed at employment. The table also lists the outputs that correspond to the projects, which

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- 1 were reviewed by the NRC Committee. These outputs were identified by the study's key
2 personnel as those which would best reflect their grant's achievements.
3

Project	Output
A. Survey of community development credit unions	A1. Valerie Harrison, Terry Ratigan, Daniel Apfel. (2008). Community Development Credit Unions Respond to the Needs of the Disability Community, In Building a Better Economic Future: A Progress Report for Individuals with Disabilities & Their Families in America (pp. 99-108). Manchester, NH: Community Economic Development Press.
	A2. World Institute on Disability. (2006). National Federation of Community Development Credit Unions "Each One, Teach Many". Facilitator's Guide. Disability Access Concepts and Practice: Building Bridges and Breaking Barriers.
B. Tax Facts and Family Disability Survey	B1. Hartnett, J. (2006). Educating Democracy: Tax and Financial Service Needs of Working Americans with Disabilities. National Disability Institute.

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	B2. Part A: Johnette T. Hartnett, Michael Morris, Judy Stengel. (2008). Real Economic Impact Tour, <i>In Building a Better Economic Future: A Progress Report for Individuals with Disabilities & Their Families in America</i> (pp. 85-98). Manchester, NH: Community Economic Development Press. Part B: National Disability Institute. (2010). Real Economic Impact Tour, 2009-2010 Annual Report. National Disability Institute.
C. Volunteer Income Tax Assistance and Financial Education Project	C1. Volunteer Income Tax Assistance and Financial Education Study Intervention Protocol Found in- Tobey Partch-Davies and Jolan Rivera. (2008). Everyday Heroes: How Taxpayers with Significant Disabilities are Building Assets, <i>In Building a Better Economic Future: A Progress Report for Individuals with Disabilities & Their Families in America</i> (pp. 45-62). Manchester, NH: Community Economic Development Press C2. Hartnett and Davies. (2010) Disability-Inclusive Asset Building: New Strategies for

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	Achieving Real Economic Impact For Americans with Disabilities. <i>In</i> Opportunities for Community Development Finance in the Disability Market. Federal Reserve Bank of Boston.
D. IDA Project Demonstration for Self employment	D1. Individual Development Account Protocol Found in- Tobey Partch-Davies and Jolan Rivera. (2008). Everyday Heroes: How Taxpayers with Significant Disabilities are Building Assets, <i>In</i> Building a Better Economic Future: A Progress Report for Individuals with Disabilities & Their Families in America (pp. 45-62). Manchester, NH: Community Economic Development Press. D2. Making Financial Connections Training Brochures: 1. Making Connections, 2. Back To Work, 3. Taking Your Credit, 4. Managing Your Money, 5. Building a Strong Future

Brief Description of the Outputs:

The first two outputs reviewed by the NRC under the survey of community development credit unions project were a book chapter and a facilitator's guide for an education training module.

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1 The book chapter (A1) summarizes and identifies how the members of the Federation of
2 Community Development Credit Unions are serving people with disability and improving
3 services and products to this community. The facilitator's guide (A2) provides an overview and
4 training on disability access concepts and practice. The distribution of this publication to
5 organizations nationwide provided background on the need and importance of serving the
6 financial needs of disabled people.

7
8 Under the tax facts and family disability survey project two publications of technical nature were
9 produced. The first (B1), a report on the tax and financial service needs of working Americans
10 with disabilities, provided a profile of the utilization and demographics of tax filing and financial
11 service activities of eligible workers with disabilities. Prior to this research, no such evidenced
12 based profile was available and this profile provided a foundation for further research now used
13 as reference for tax assistance grants serving taxpayers with disabilities across the country. The
14 project's second output (B2), the Real Economic Impact (REI) Tour, was described in two
15 documents. The REI Tour is a public and private partnership of federal, state, and local
16 organizations that promotes self-determination and full inclusion of Americans with disabilities
17 in building a healthy economic future for themselves.

18
19 The next two outputs produced under the volunteer income tax assistance and financial education
20 project were a study intervention protocol and a paper. The Volunteer Income Tax Assistance
21 and Financial Education Study Intervention Protocol (C1) was a comprehensive protocol of
22 financial coaching designed to improve financial management behaviors of persons with
23 disabilities consistent with financial security and asset holdings. The paper (C2) was published
24 by the Federal Reserve Bank of Boston to raise awareness of the existing market of people with

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1 disabilities to the community development, non-profit, and private financial institutions. The
2 paper used the Real Economic Impact Tour and Volunteer Income Tax Assistance and Education
3 Study as examples of partnerships between community-development and disability service
4 organizations and implementation strategies that enhance the economic and social well-being of
5 low-income taxpayers with disabilities.

6
7 The final two outputs reviewed were another study intervention protocol and training brochures
8 produced as part of the IDA Project Demonstration for Self-Employment. The Individual
9 Development Account Protocol (D1) was intended to aid persons with disabilities to save money
10 from earnings for home ownership, post-secondary education, and business development. It was
11 developed to be integrated with community development entities by making their programs more
12 universally accessible and adapting some of their program parameters for persons with
13 disabilities. The Making Financial Connections training brochures (D2) were targeted to
14 community development and rehabilitation specialists in an effort to build a more
15 comprehensive, disability inclusive infrastructure linking the two sectors. They provided
16 introductory, interdisciplinary training and information on assistance programs and resources
17 (Making Financial Connections), returning to work (Back to Work), available tax credits and
18 services (Taking Your Credit), effects of financial decisions (Your Money, Your Choices), and
19 asset building programs and reaching financial goals (Building a Strong Future).

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Grant Title: Medicaid Quality Indicators for Individuals with Disabilities

Grant Award Number: H133A040016

Grantee: George Mason University

Grant Mechanism: Disability and Rehabilitation Research Project

Grant Start and End Dates: January 1, 2005 to June 30, 2009

Total Direct Cost: \$1.2 Million

Abstract: The purpose of this 5-year study was to develop and test comparative measures of quality, access, and satisfaction for their use with people with disabilities as well as person in the general population. The study was designed as a joint project of George Mason University (Virginia), the Delmarva Foundation for Medical Care (Maryland), Kaiser-Permanente Center for Health Research (Oregon), and Baylor University (Texas).

The first component of the study was intended to refine a computer program that mines state Medicaid claims data to identify people who are very likely to face challenges getting the care they need as a consequence of a disability. The researchers planned to verify the accuracy of the computer program by surveying Medicaid beneficiaries in California about their ability to participate in community activities, live independently, and visit the doctor. The objective of the second study component was to review the two most widely-used health plan quality indicators,

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1 the CAHPS® survey on consumer reported quality of care, and the HEDIS® Medicaid measures
2 to identify questions and measures (such as rates of preventive care) that are especially
3 appropriate for people with disabilities and that are statistically valid even when a relatively
4 small number of people are being looked at. The intent of the third component of the study was
5 to interview working age adults with disabilities in Oregon, California and Baltimore-
6 Washington DC, to learn what types of information they would like to know when selecting a
7 health plan, and how they would like to obtain that information.

8
9 This overall aim of the study was to improve the field's ability to help people make informed
10 choices of health plans; help the health plans to compare their performance against benchmarks;
11 help health plans to measure the progress of their quality improvement programs; and help states
12 to monitor health plan performance.

13
14 **Research Projects and Outputs Reviewed:** Annual Performance Report databases that were
15 provided to NRC and which date back to FY 2006-2007 identified seven outputs produced by
16 this grant. These included a publication, four measures, a software program, and patent
17 application for the software program.

18
19 The following table shows the three main projects that were carried out under the grant, which
20 were aimed at NIDRR's key research domain of health and function. The table also lists the
21 outputs that correspond to the projects and which were reviewed by the NRC Committee. These
22 outputs were identified by the study's key personnel as those which would best reflect their
23 grant's achievements.

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Projects	Outputs
A. Case Identification	A1. Palsbo SE, Sutton C, Mastal MF, Johnson S, Cohen A. 2008. Identifying and Classifying People with Disabilities Using Claims Data: Further Development of the Access Risk Classification System (ARCS) Algorithm. <i>Disability and Health Journal</i> . 1(4):215-223.
	A2. Patent application #20070185734 "Using diagnoses to identify adults with disabilities."
B. Assessment of Health Plans and Providers by People with Activity Limitations (AHPPPAL) and administrative measures.	B1. Palsbo SE, Hurtado MP, Levine RE, Barrett KA, Mastal MF. 2010. Enabling a Survey of Primary Care to Measure the Health Care Experiences of Adults with Disabilities. <i>Disability and Rehabilitation</i> . e-Print ahead of publication. PMID: 20528104.
	B2. Quality Indicators for Individuals with Disabilities in Managed Care (Administrative measures – grey paper)
C. Comparative reporting tool (Plan-reported indicators, Comparative reporting tools and Consumer-reported indicators)	C1. Palsbo SE, Diao G, Palsbo GA; Tang L, Rosenberger WF, Mastal MF. 2010. Case-mix Adjusted and Enabled Reporting of CAHPS Surveys – The AHPPPAL Dashboard. <i>Archives of Physical Medicine and Rehabilitation</i> . 91(9):1339-46.

Brief Description of the Outputs:

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1 The first output (A1) and second output (A2) were both from the project on Case Identification.

2 The first output (A1) reviewed was a journal article which described results of an initiative to
3 "refine and revalidate a software algorithm, the Access Risk Classification System (ARCS),
4 using automated claims data to classify people into one of four categories based on the probable
5 need for care coordination or health system accommodations". The algorithm's sensitivity and
6 specificity were evaluated by comparing the predicted classification against self-report. Results
7 showed the overall classification range from good to fair. The second output (A2) was a patent
8 application for the algorithm that was under review by the U.S. Patent and Trade Office. Using
9 and combining existing sources of data, ARCS can quickly and correctly identify individuals
10 needing extra medical assistance, such as people with disabilities.

11
12 The third output (B1) and fourth output (B2) were from the project on Assessment of Health
13 Plans and Providers by People with Activity Limitations (AHPPPAL). The third output (B1) was
14 a journal article from a study which field-tested adapted items of the Consumer Assessment of
15 Healthcare Providers and Systems (CAHPS®) to enable this existing instrument to capture the
16 healthcare experiences of adults living with disabilities. Results showed that 38% of respondents
17 had learning disabilities, which can interfere with access to health care services. Palsbo et al
18 concluded that the study demonstrated the feasibility of enabling an existing instrument for
19 persons with mixed functional limitations and severity.

20 Data gathered from such an instrument could be used to identify and improve specific practices
21 to provide better quality medical care for people with disabilities.

22
23 The fourth output (B2), also from the AHPPPAL project, was a compilation of quality measures
24 for individuals with disabilities that resulted from an initiative to develop and field test quality

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measures derived from administrative and survey data sources, building on HEDIS® and CAHPS®. Collection of these measures created a foundation from which further exploration and testing of their relevance for individuals with disabilities could occur. This grantee alone developed five peer-reviewed articles from this foundation.

The fifth output (C1) reviewed was a journal article that reported results of a study to develop activity limitation clusters for case mix adjustment of health care ratings and as a population profiler. This output comes from the Comparative Reporting Tool project. Using the same respondent database as in output B1 above, a principal components analysis created four clusters of activity limitations. An analysis of scores of the enabled version of the CAHPS with the case mix adjustment showed that disability caused a greater bias on health plan ratings than did demographic factors. According to Palsbo et al, the new enabled report, called the Assessment of Health Plans and Providers by People with Activity Limitations, is superior to the older CAHPS when assessing individuals with disabilities.

DRAFT GRANT/OUTPUT SUMMARY

1 **Grant Title:** Persons Aging with Hearing and Vision Loss

3 **Grant Award Number:** H133A020701

5 **Grantee:** Mississippi State University

7 **Grant Mechanism:** Disability and Rehabilitation Research Projects

9 **Grant Start and End Dates:** November 1, 2002 to October 31, 2009

11 **Total Direct Cost:** \$2,505,000

13 **Abstract:** The RRTC on Blindness and Low Vision at MSU, in collaboration San Diego state
14 University, and the Helen Keller National Center for Deaf-Blind Youths and Adults in Sands
15 Point, established a consortium Disability & Rehabilitation Research Project (DRRP) on Persons
16 Aging with Hearing & Vision Loss. The collaborative effort focused on the exploration of
17 strategies to improve outcomes for persons who are blind or visually impaired or who are deaf or
18 hard of hearing and who are now experiencing a secondary onset of hearing loss or vision
19 impairment as a result of the aging process. The 5-year project was involved in the following
20 priorities: P.1) Investigating the prevalence of age-related onset of deafness among older
21 American blind individuals and age-related onset of blindness among older American deaf
22 individuals and the impact on the employment and community integration options, including
23 more viable communication systems for each population; P.2) Identifying and evaluating
24 technology and service delivery options, such as transportation, housing, and community

DRAFT GRANT/OUTPUT SUMMARY

1 integration activities for individuals with early onset deafness or blindness and late onset hearing
2 or vision loss and their effectiveness with persons experiencing secondary sensory loss resulting
3 from aging; P.3) Identifying and evaluating access to use of technologies, including assistive
4 devices and telecommunication or other existing communication systems, such as tactile
5 interpreter support, needed to assist persons with early onset deafness or blindness and late onset
6 hearing or vision loss and their effectiveness with persons experiencing secondary sensory loss
7 resulting from aging; and P.4) Using available dissemination mechanisms, with appropriate
8 assistive technical modification, disseminating findings, and developing strategies to educate
9 both consumers and providers, especially vocational rehabilitation workers, in use of these
10 techniques.

11
12 **Research Projects and Outputs Reviewed:** Annual Performance Report databases that were
13 provided to NRC and which date back to FY 2006-2007 identified thirteen outputs produced by
14 this grant, eleven journal articles, one newsletter, and one website.

15
16 The following table shows the four main projects that were carried out under the grant, which
17 were aimed at many of NIDRR's key research domains. Project A was aimed at employment,
18 participation and community living, and demographics. Projects B and D were aimed at
19 participation and community living. Project C was aimed at technology. The table also lists the
20 outputs that correspond to the projects and which were reviewed by the NRC Committee. These
21 outputs were identified by the study's key personnel as those which would best reflect their
22 grant's achievements.

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Project	Output
A. Prevalence of Hearing and Vision Loss in Seniors and the Impact on Employment and Community Integration	A1. Capella-McDonnall, M. & LeJeune, B.J. (2008). Employment among older adults with combined hearing and vision loss. Journal of Applied Rehabilitation Counseling, 39(3), 3-9.
	A2. Sansing, W.K. (2010). An Overview of Hearing, Vision and Dual Sensory Impairment Prevalence in the U.S. Being submitted for publication this month.
B. Technology and Service Delivery Options	B1. Persons Aging With Hearing And Vision Loss Newsletter.
	B2. LeJeune, B. J. (2010). Persons aging with hearing and vision loss: Thoughts and considerations from consumer focus groups. Manuscript accepted for publication in the Fall issue of the AER- Journal of Research and Practice in Visual Impairment and Blindness
C. Identification and Evaluation of Access to Technology	C1. LeJeune, B.J., Steinman, B.A., & Mascia, J. (2003) Enhancing socialization of older people experiencing loss of both vision and hearing. Generations. XXVII (1) pp 95-97.
	C2. Capella-McDonnall, M. E. (2005). The effects of single and dual sensory loss on symptoms of depression in the elderly. International Journal of Geriatric Psychiatry, 20, 855-861.
D. Dissemination	D1. Newsletter Series available on RRTC website
	D2. National Conference in 2006 entitled Persons Aging with Hearing and Vision Loss: Creating Roads to Independence Proceedings

DRAFT GRANT/OUTPUT SUMMARY

Brief Description of the Outputs:

The first two journal articles produced from the Prevalence of Hearing and Vision Loss in Seniors and the Impact on Employment and Community Integration project analyzed employment and prevalence of hearing and vision impairment among older adults. Capella-McDonnall and LeJeune (2008) performed an exploratory study which compiled data on the employment status and experiences of a group of older adults with combined hearing and vision loss. Their results indicated that many of these adults do work or want to work and that accommodations, assistive technology, higher education levels, and changing jobs or type of work are associated with continued employment. The second article (A2) was a literature review on the prevalence of hearing, visual, and dual sensory impairment among seniors in the U.S. It found that nationally representative survey estimates produce varied prevalence totals but all demonstrate increased numbers of people age 55 and over with all types of sensory loss.

Under the technologies and service delivery options project, the NRC reviewed two outputs. The first was a newsletter (B1) updating research participants, service providers, and stakeholders on the project including survey status and results. The second was a journal article (B2) discussing the issues identified by consumer focus groups (older adults self identified with both hearing and visual impairments) concerning services and access to technology that they have experienced. There appeared to be a perceived lack of accommodations in programs for older blind adults related to hearing loss and a lack of knowledge about visual impairment from the deaf or hard of hearing who acquired the vision loss later in life.

DRAFT GRANT/OUTPUT SUMMARY

1 The next two outputs were journal articles produced under the third project (Identification and
2 Evaluation of Access to Technology). LeJeune et al. (2003) focused on enhancing socialization
3 of older people experiencing loss of both vision and hearing, particularly through suggestions for
4 improved communication including assistive technologies. Capella-McDonnall (2005) analyzed
5 the effects of single and dual sensory loss on symptoms of depression in the elderly. Results
6 found that elderly with dual sensory loss were not significantly more likely than those with
7 vision loss, but were significantly more like than those with hearing loss to experience symptoms
8 of depression.

9
10 The final two outputs reviewed under the dissemination project were a newsletter series (D1) and
11 a national conference (D2). The Persons Aging with Hearing and Vision Loss (PAHVL)
12 newsletter series were distributed to research participants, service providers, and stakeholders.
13 They contained updates, preliminary research results, and helpful information. The national
14 conference was entitled Creating Roads to Independence for Persons Aging with Hearing and
15 Vision Loss. A variety of new information was presented on topics including but not limited to
16 the basics of sensory loss, use of support service providers, communication strategies, assistive
17 technology and psycho-social adjustment. Evaluations were positive and drew organizers to put
18 on a second conference.

DRAFT GRANT/OUTPUT SUMMARY

1 **Grant Title:** Efficacy of Pressure Garment Therapy After Burns

3 **Grant Award Number:** H133G050022

5 **Grantee:** University of Washington

7 **Grant Mechanism:** Field Initiated Project

9 **Grant Start and End Dates:** October 1, 2005 to September 30, 2009

11 **Total Direct Cost:** \$450,000

13 **Abstract:** The objective of this project was to determine the efficacy of custom-fit pressure
14 garment therapy in the prevention of hypertrophic scarring in healed burns through a
15 randomized, controlled trial. Pressure garments are the common therapy used today to minimize
16 hypertrophic scarring, one of the most devastating outcomes following burn injury. However,
17 these garments are unattractive, expensive and uncomfortable, and their use needs to be validated
18 by rigorous research.

20 **Research Projects and Outputs Reviewed:** Annual Performance Report databases that were
21 provided to NRC and which date back to FY 2006-2007 identified one output produced by this
22 grant, one instrument. In addition the grantee reported one journal article to the NRC Committee.

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The following table shows the project that was carried out under the grant, which was aimed at NIDRR's key research domain of health and function. The table also lists the output, a journal article, that corresponds to the project and which was reviewed by the NRC Committee. This output was identified by the study's key personnel as that which would best reflect their grant's achievements.

Project	Output
A. Efficacy of Pressure Garment Therapy After Burns	A1. Engrav LH, Heimbach DM, Rivara FP, Moore ML, Wang J, Carrougner GJ, Costa B, Numhom S, Calderon J, Gibran NS. 2010. 12-Year within-wound study of the effectiveness of custom pressure garment therapy. <i>Burns</i> . 36: 975-983 (April).

Brief Description of the Output:

Engrav et al. (2010) described the effectiveness of custom pressure garment therapy using a randomized within-wound comparison over a 12-year period. The article found that custom pressure garment therapy is effective, but clinical benefit is restricted to those with moderate or severe scarring. In addition, the article underlined the limitations that may have affected the paucity of prior randomized control trials confirming the effectiveness of custom pressure garment therapy. This study was the first to ever utilize a within-wound protocol.

DRAFT GRANT/OUTPUT SUMMARY

Grant Title: A longitudinal study for hospitalization, pressure ulcers, and subsequent injuries after spinal cord injuries.

Grant Award Number: H133G050165

Grantee: Medical University of South Carolina

Grant Mechanism: Field Initiated Project

Grant Start and End Dates: June 1, 2007 to May 31, 2010

Total Direct Cost: \$449,984

Abstract: The purpose of this project was to perform a longitudinal study to identify protective and risk factors associated with the onset of multiple types of adverse health events among a large sample of individuals with SCI. The onset of SCI increases the risk for the development of a number of secondary conditions that may adversely impact an individual's life and even result in early mortality.

Predictor variables were first measured over a 10-month period in 1997-1998, including: (a) biographical status, (b) injury status, (c) psychological status, (d) environmental factors, and (e) health behaviors. Several health outcomes measures were also used. During follow-up, multiple outcome measures were administered, with a focus on adverse events -- pressure ulcers, subsequent injuries, hospitalizations, and treatments. Structural equation modeling was

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performed to develop risk models for each outcome. A consumer advisory committee met to review instrumentation and made recommendations regarding all components of the project.

This project addresses important National Institute on Disability and Rehabilitation Research (NIDRR) priorities on health and function. The ultimate study goal was to enhance the lives of people with SCI by identifying the risk and protective factors associated with adverse health events to serve as a foundation for prevention efforts by rehabilitation and public health professionals. Consumers will be directly empowered to improve their own health by being provided with concrete information and recommendations to promote better health and avoid preventable secondary health complications

Research Projects and Outputs Reviewed: Annual Performance Report databases that were provided to NRC and which date back to FY 2006-2007 identified fourteen outputs produced by this grant, twelve journal articles, one newsletter, and one website.

The following table shows the project that was carried out under the grant, which was aimed at NIDRR's key research domain of health and function. The table also lists the outputs, two journal articles, that correspond to the project and which were reviewed by the NRC Committee. These outputs were identified by the study's key personnel as those which would best reflect their grant's achievements.

Project	Output
A. A longitudinal study for	A1: A1. Krause, JS and Saunders, LL. 2009. Risk of

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hospitalizations, pressure ulcers, and subsequent injuries after spinal cord injuries.	hospitalizations after SCI: Relationship with biographic, injury, educational, and behavioral factors. <i>Spinal Cord</i> . 47: 692-697. A2. Krause, JS, Reed, KS, McArdle, JJ. 2010. A structural analysis of health outcomes after spinal cord injury. <i>The Journal of Spinal Cord Injury</i> . 33(1): 22-32.
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Brief Description of the Outputs:

The first output (A1) reviewed by the NRC was a journal article which aimed to identify variables and individual health behaviors associated with hospitalization after spinal cord injury. Two biographical and injury characteristics were found to be associated with hospitalization: race and SCI severity. After controlling for these, three behavioral factors were found to be significantly associated with hospitalization: persons who used prescription medications, those who engaged more in smoking behaviors, and persons who reported more SCI-specific health behaviors.

The second output (A2) reviewed was another journal article which developed a measurement model both through exploratory and confirmatory factor analysis of health domains and a latent model linking basic biographical, injury, and educational characteristics with health outcomes for persons with spinal cord injury. The study used structural equation modeling in identifying common factors for health outcomes, distinct factors relating to secondary conditions, and factors relating to health impact. Six health outcome domains were identified in the study and were found to have significant relationship with biographical, injury, and educational status. The

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- 1 composite scores generated from multiple indicators provide more informative and stable
- 2 outcome scores than does utilization of single indicators.

3

DRAFT GRANT/OUTPUT SUMMARY

Grant Title: Black-white Disparities in Stroke Rehabilitation

Grant Award Number: H133G050153

Grantee: National Rehabilitation Hospital/Medstar Research Institute

Grant Mechanism: Field Initiated Projects

Grant Start and End Date: October 1, 2005 to September 30, 2009

Total Direct Cost: \$396,165

Abstract: The purpose of this 3-year study was to examine differences in (1) how black and white stroke rehabilitation patients differ in terms of their clinical profiles, the care they receive, and their outcomes and (2) how rehabilitation care and outcomes can be optimized for both groups. Our goal was to translate these findings into an actionable quality improvement plan that would enhance care and outcomes for all black and white stroke rehabilitation patients.

The proposed study capitalized on a unique comprehensive stroke rehabilitation database (N = 1161) containing detailed patient, intervention, and outcomes data assembled from 2001 to 2003 under the auspices of the NIDRR-sponsored Post-Stroke Rehabilitation Outcomes Project. This database contains extraordinarily detailed data on rehabilitation care processes and treatments that allowed investigators to peer into the practice of stroke rehabilitation care and to dissect the processes of care that might be different for whites and blacks. This practice-based evidence

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(PBE) method assured clinical buy-in and ownership of the study's findings needed to assure the implementation of new quality improvement initiatives based on the study's findings. The project team also proposed an evaluation protocol to confirm the effectiveness and predictive validity of any proposed practice changes.

Research Projects and Outputs Reviewed: The Annual Performance Report databases that were provided to the NRC, which date back to FY 2006-2007, identified one output produced by this grant, one statistical technique. In addition the grantee reported two related journal articles to the NRC Committee.

The following table shows the project that was carried out under the grant. The project was aimed at the health and function domain. The table also lists the output that corresponds to the project, which was reviewed by the NRC Committee. This output was identified by the study's key personnel as that which best reflect their grant's achievements.

Project	Output
Black-White Disparities in Stroke Rehabilitation	Part A- Horn SD, Deutscher, D., Smout, RJ, DeJong, G., Putnam, K. (2010). Black-white differences in patient characteristics, treatments, and outcomes in inpatient stroke rehabilitation (2010). Arch Phys Med Rehabil, 91, 1712-1721.

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	Part B- Deutscher, D., Horn SD, DeJong, G., Putnam, K. (2010). Black-white disparities in motor function outcomes taking into account patient characteristics, nontherapy ancillaries, therapy activities, and therapy interventions. Arch Phys Med Rehabil, 91, 1722-1730.
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Brief Description of the Output:

The two journal articles reviewed by the NRC were considered as a pair (one output) since all the information provided for the first article applies to the second article. The journal articles applied a practice-based evidence approach in analyzing disparities in rehabilitation services and outcomes. The first article focused on black-white differences in characteristics and factors in patient stroke rehabilitation and the second regresses these variables on motor function outcomes.

Racial differences were found in certain aspects of service receipt and outcomes with both blacks and whites benefiting in different ways. However, it was not race itself which made a difference in outcomes, but the interventions that did. This project thus shows the importance using a practice-based evidence approach in studying the process of care and dealing with issues related to bias in observational studies.

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Grant Title: Development of Intelligent Personal Activity Management and Prompting Applications for Individuals with Cognitive Disabilities

Grant Award Number: H133G050313

Grantee: Eugene Research Institute

Grant Mechanism: Field Initiated Project

Grant Start and End Dates: October 1, 2005 to September 30, 2009

Total Direct Cost: \$499,852

Abstract: This project built on the successful development of the Picture Planner icon-driven personal activity management application, supported in part by previous NIDRR funding. One of the conclusions of the field testing that led to the development and testing of that application was the need for intelligent activity planning and prompting applications that combine cognitively accessible software design with innovative artificial intelligence approaches to provide smart applications for life management and decision making. The goal of this project was to use a consumer-driven, participatory design process to build on that foundation and develop a prototype smart planning and prompting software package for implementation on desktop and handheld platforms. Major objectives included:

1) Year 1: Needs assessment focus groups with 20 individuals with disabilities and 10 care

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1 providers. Goal was to survey priorities from the consumer and assistant perspectives for features
2 of a smart management system.

3 2) Years 1-2: Development of proof of concept design and validation process to guide
4 subsequent development of smart features.

5 3) Year 2-3: Prototype application development, emphasizing integration of intelligent
6 prompting elements into the desktop Picture Planner application and subsequent implementation
7 on handheld systems.

8 4) Year 3: Comparison study of smart versus standard methods of activity planning using
9 random assignment of 20 Consumer Development Group members.

10 5) Year 3: Preparation of final strategic white paper addressing technical challenges and
11 directions for further development of smart life skills applications incorporating artificial
12 intelligence methods.

13
14 The primary outcome of this project was a field-tested and experimentally evaluated intelligent
15 life skills management system enabling people with cognitive disabilities to improve their
16 competence at daily activity management and enhance their community integration. In addition
17 to a commercially viable desktop and handheld application, the white paper produced in
18 Objective 5 provided source material for submission of at least three papers to refereed journals
19 and conference presentations, and for written and electronic products targeting a variety of
20 audiences including consumers, families, researchers, educators, and developers.

21
22 **Research Projects and Outputs Reviewed:** Annual Performance Report databases that were
23 provided to NRC and which date back to FY 2006-2007 identified nine outputs produced by this

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grant, one journal article, one proceedings, three audiovisual materials, one prototype, one network product, one product in marketplace, and one website.

The following table shows the project that was carried out under the grant, which was aimed at NIDRR's key research domain of technology. The table also lists the outputs that correspond to the project and which were reviewed by the NRC Committee. These outputs were identified by the study's key personnel as those which would best reflect their grant's achievements.

Project	Output
A. Development of Intelligent Personal Activity Management and Prompting Applications for Individuals with Cognitive Disabilities	A1. Software application: Picture planner: A cognitively accessible personal activity scheduling organizer
	A2. Assets conference proceedings on the Picture Planner

Brief Description of the Outputs:

The first output (A1), Picture Planner, is a personal organizer application designed for individuals who either have limited or no reading ability, or need a simplified and graphically driven user interface. The target population were individuals with significant cognitive disabilities such as mental retardation and autism. The heterogeneity of this population, the challenge of representing complex concepts in graphic form, and lack of standards or a universally understood icon system makes this sort of cognitively accessible application difficult.

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1 Despite the preponderance of visual scheduling applications, there existed no similarly capable
2 and cognitively accessible application. The second output (A2), a publication, describes the
3 design elements and field test results which advanced the cognitive accessibility of the icon-
4 driven Picture Planner. Users with significant cognitive disabilities were shown to be able to
5 learn to use and benefit from an accessible computer-based self-management application such as
6 Picture Planner.

DRAFT GRANT/OUTPUT SUMMARY

1 **Grant Title:** Driving after stroke

3 **Grant Award Number:** H133G050134

5 **Grantee:** Wayne State University

7 **Grant Mechanism:** Field Initiated Projects

9 **Grant Start and End Date:** October 1, 2005 to May 31, 2009

11 **Total Direct Cost:** \$330,474

13 **Abstract:** A variety of factors influence return to driving after stroke, only some of which
14 accurately reflect the ability to drive safely. Although current methods can enhance accuracy in
15 predicting fitness to drive, decisions about driving often are made independent of this
16 information. Moreover, little research has focused on unwarranted barriers to driving or the
17 consequences of having stopped. No study has examined the bases on which survivors make
18 decisions about resumption of driving as it relates to objective driving fitness and community
19 integration.

21 This study sampled pairs of survivors and their significant others recruited at inpatient discharge,
22 from the outpatient clinic of an urban rehabilitation hospital, and from the metropolitan
23 community. Barriers to driving, driving status, and community integration were assessed 6
24 months post stroke. A subsample also underwent a comprehensive driving evaluation. The

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objectives were to identify the barriers to driving after stroke and the extent to which these barriers influence driving status (i.e., decision to drive), actual driving risk, and community integration. The long-term goal was the development of interventions that maximize independence and community integration, while protecting the public and survivor safety. The study of barriers to driving facilitates valid evaluation of fitness to drive and the psychoeducation of survivors and their significant others regarding decisions to resume or cease driving after stroke.

Research Projects and Outputs Reviewed: The Annual Performance Report databases that were provided to the NRC, which date back to FY 2006-2007, identified five outputs produced by this grant, five journal articles.

The following table shows the project that was carried out under the grant. The project was aimed at the participation and community living domain. The table also lists the outputs, two journal articles, that correspond to the project, which were reviewed by the NRC Committee. These outputs were identified by the study's key personnel as those which best reflect their grant's achievements.

Project	Output
Driving after stroke	1. Griffen, Rapport, Bryer, Scott. (2009). Driving Status and Community Integration After Stroke. Topics in Stroke Rehabilitation, 16(3): 212-221.

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Project	Output
	2. McKay, Rapport, Bryer, Casey. (in press). Self-evaluation of driving simulator performance after stroke. Topics in Stroke Rehabilitation

Brief Description of the Outputs:

Griffen et al. (2009) investigated the effects of driving cessation on community integration after stroke and assessed gender and social support as potential moderators of this effect. Prior research had mostly examined a single subjective outcome rather than assessing community integration as a multidimensional outcome including subjective and objective domains. The study found that driving status had a substantial influence on community integration after stroke and that social support facilitated this integration but did not buffer the effects of driving cessation. Men and women were found to resume driving at equal rates, but driving cessation showed differential effects for men and women in regard to community integration, with women experiencing less strong adverse effects.

McKay et al. (in press) examined self-awareness of driving simulator and neuropsychological performance among stroke patients compared to healthy controls. Despite the potential dangers with premature return to driving after stroke, very little research had previously examined the relationship between impaired self-awareness (ISA) and driving. The driving simulators provided the opportunity for novel application of metacognitive self-evaluations in prediction and postdiction of performance and insight into the impact of experience on accurate self-

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1 awareness of deficits. The findings support the potential use of driving simulators as a useful and
2 safe method of assessing and improving stroke survivor's ISA.

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1 **Grant Title:** Functional Effects of Bifocal Use: Implication for Falling Intervention

3 **Grant Award Number:** H133G050340

5 **Grantee:** University of Wisconsin-Milwaukee

7 **Grant Mechanism:** FIP

9 **Grant Start and End Dates:** October 1, 2005 to September 30, 2009

11 **Total Direct Cost:** \$320,631

13 **Abstract:** This project directed an integrated set of research activities to address a seriously
14 under considered factor in falls research, the use of bifocal lenses. This project focused on new
15 users of bifocal glasses, typically individuals in their 4th or 5th decade and targeted a better
16 understanding of falls intervention strategies related to eyeglass wear. The five primary goals of
17 the study were: 1) Measure outcomes of bifocal use; 2) Understand the process of adaptation to
18 new bifocals; 3) Explore brain function as a potential explanatory variable; 4) Draft
19 recommendations for clinical practice and design, and: 5) Disseminate scientific papers and
20 presentations to inform research, device development, and practice. In Phase 1 of the study,
21 researchers longitudinally studied how adaption to multifocal lens affected depth perception,
22 edge-contrast, and functional mobility. In Phase 2, researchers took functional MRI scans of new
23 users during adaptation. Study recommendations were articulated not only for multifocal lens

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wearers but for the producers of lenses and biomedical engineers.

Research Projects and Outputs Reviewed: Annual Performance Report databases that were provided to NRC and which date back to FY 2006-2007 identified one output produced by this grant, a diagnostic instrument. In addition the grantee reported five outputs, four technical reports and one summary presentation, to the NRC Committee.

The following table shows the three projects that were carried out under the grant. The projects were aimed at NIDRR's key research domain of health and function. The table also lists the outputs that correspond to the projects and which were reviewed by the NRC Committee. These outputs were identified by the study's key personnel as those which would best reflect their grant's achievements.

Project	Output
A. Functional adaptation in new wearers of multifocal lenses	A1. The DGI-M (Dynamic Gait Index - Modified)
	A2. Functional Performance Effects of Multi-focal Lens Use with New Multifocal Lens Wearers
B. Brain response to upper and lower lens conditions fMRI analysis of bifocal wearers.	B1. The Upper and Lower Visual Field Depth Perception Performance Measure
	B2. Differential of Depth Perception Performance Between Single and Multifocal Lens Use in a Pre-fMRI Paradigm
C. fMRI analysis of bifocal wearers	C1. ACRM Presentation of the Multifocal Lens Project: Implications for Disability

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	C2. Preliminary fMRI Brain Scan Demonstration of Attentional Differences Between Upper and Lower Visual Fields in Experienced Multifocal Lens Wearers
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Brief Description of the Outputs:

The first output (A1) and the second output (A2) are results of the project on functional adaptation to multifocal lenses. The first output (A1) reviewed was a tool, the Dynamic Gait Index – Modified (DGI-M). The DGI-M is a modification of the original DGI, a well regarded tool for measuring functional gait in older adults used to discriminate between performance with and without wearing multifocal lens glasses. Modifications included increasing the scoring scale, adding tasks targeted to wearers of multifocal lens, redesigning the walkway and obstacles involved in the tasks, and adding a subjective response questionnaire to gauge discomfort. According to its creators, the DGI-M improves on the original by also effectively measuring functional gait in younger (ages 40-59) participants.

The second output (A2) was a technical report from a study that explored how visual and function gait performance were affected when middle aged users of single lens glasses transitioned to multifocal lenses. Participants used single lens glasses and had been prescribed multifocal lenses, but had not worn them prior to the study. Participants were tested using the Howard-Dohlman Depth Perception apparatus, the Melbourne Edge Test, and the modified Dynamic Gait Index (DGI-M). Researchers found significant difference between single lenses and multifocal lenses in depth perception, contrast edge sensitivity, and functional gait.

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1 Researchers concluded that transition to multifocal lenses significantly degraded visual and
2 functional gait performance in middle aged adults, but did not seem to increase risk of falling.

3
4 The third output (B1) and fourth output (B2) were both technical reports from the brain response
5 project. The third output (B1) related how researchers developed a new 3D depth perception
6 paradigm. The paradigm involves a set of four 2-color, 3D circles, one of which appears either
7 closer or farther away from the participant. Researchers also developed an apparatus to control
8 participants' heads in order divide images between upper lenses and lower lenses. Testing of the
9 final paradigm resulted in significant differences for lens type (single versus multifocal) and
10 wearer group (multifocal wearers vs. nonmultifocal wearers). This measure allowed for creation
11 of a software based data collection scheme that could be transferred to an fMRI. Researchers
12 believe this measure may lead to better understanding of depth perception and better intervention
13 designs to prevent falls.

14
15 The fourth output (B2) was from a study on differences in single lens versus multifocal lens use
16 while: 1) responding to targets in the upper versus lower visual field, and 2) responding to targets
17 with the presence of a visual distracter. Using both single and multifocal lens participants
18 identified a circle, either in their upper or lower visual field, which was closer or farther away
19 than other circles. At times participants made judgments while discriminating against a visual
20 distracter. Statistical analysis of the data demonstrated significant performance differences
21 between single and multifocal lenses. Results of this study suggest a difference in attentional
22 capability of single lens and multifocal lens user, which may be exacerbated by distraction.

DRAFT GRANT/OUTPUT SUMMARY

1 The final two outputs (C1 and C2) were related to the fMRI analysis project. The fifth output
2 (C1) was a presentation of a summary of output A1 at the 2010 American Congress of
3 Rehabilitation Medicine annual meeting. The summary included background, goals, methods,
4 results, conclusions, and implied future research directions. During the presentation, researchers
5 highlighted the potential implications of their work to improve understanding of the relationship
6 between use of multifocal lenses and falling for people with disabilities.

7
8 The sixth output (C2) was a technical report from an exploratory study of different attentional
9 patterns for upper and lower visual fields in long time multifocal lens user versus non-multifocal
10 lens users. An fMRI was used to create maps of participants' brains, then participants completed
11 a nonattentional task and an attentional task. The areas of the brain activated by each task were
12 recorded. Results indicated that the long time multifocal lens users had different attentional
13 patterns for upper and lower visual areas, while non-multifocal lens did not have different
14 patterns.

DRAFT GRANT/OUTPUT SUMMARY

1 **Grant Title:** Inclusive Indoor Play

3 **Grant Award Number:** H133G040324

5 **Grantee:** Tech Research Corp, Georgia Tech

7 **Grant Mechanism:** Field Initiated Projects

9 **Grant Start and End Date:** August 1, 2005 to December 31, 2005

11 **Total Direct Cost:** \$293,324

13 **Abstract²:** This study's intent was to learn about the needs of indoor play for children with and
14 without disabilities in order to design universal play things that can benefit all children. The
15 project researched indoor play environments, developed universal design play guidelines, and
16 designed models of play environments that are safe and accessible to all children. It researched
17 play and the play environment through literature review, existing products, existing play
18 environments, focus group interviews with participants, expert consultations, children's play
19 designs, and testing of full-scale simulated play environments. The second year of the project
20 focused on development of design concepts, construction of refined design in full scale, and
21 testing with users. The final year of the project was dedicated to prototype construction and
22 testing.

² This abstract was adapted from the project abstract found on naric.com

DRAFT GRANT/OUTPUT SUMMARY

Research Projects and Outputs Reviewed: The Annual Performance Report databases that were provided to the NRC, which date back to FY 2006-2007, identified eight outputs produced by this grant, four proceedings, one journal article, one checklist, one invention, and one rating scale.

The following table shows the project that was carried out under the grant. The project was aimed at the participation and community living domain. The table also lists the outputs that correspond to the project, which were reviewed by the NRC Committee. These outputs were identified by the study's key personnel as those which would best reflect their grant's achievements.

Project	Output
A. Inclusive Indoor Play	A1. Endicott, Sarah, Kar, Gourab, Mullick, Abir. (2009). Inclusive Indoor Play: Children at Play. Human Factors and Ergonomics Society Annual Meeting Proceedings, 53(19):1527-1531.
	A2. Mullick, Abir and Grubbs, R.L. (2009). Inclusive Indoor Play: Play and Playthings. Human Factors and Ergonomics Society Annual Meeting Proceedings, 53(19):1537-1540.

Brief Description of the Outputs:

DRAFT GRANT/OUTPUT SUMMARY

1 The two outputs reviewed by the NRC were 2009 Human Factors and Ergonomics Society
2 Conference Proceedings. The first output (A1) identified and analyzed five play aspects while
3 children with and without disabilities interacted with a variety of playthings in a full-scale play
4 environment. Results suggested that there exists a correlation between independence in play,
5 level of assistance needed, and effort required to play. Observations regarding the level of
6 difficulty and fun playing with different things were used to determine plaything components
7 that contribute to inclusive indoor play. The second output (A2) summarizes the results from
8 focus group interviews which offers information about play, indoor play, and inclusive indoor
9 play. The results of the focus group interviews produced a comprehensive list of design and
10 evaluation criteria for inclusive playthings.

11

DRAFT GRANT/OUTPUT SUMMARY

1 **Grant Title:** Interference in Hearing Aids from Digital Wireless Telephones

3 **Grantee:** Advanced Hearing Concepts

5 **Grant Award Number:** H133G050228

7 **Grant Mechanism:** Field Initiated Project

9 **Grant Start and End Dates:** November 1, 2005 to October 31, 2009

11 **Total Direct Cost:** \$447,600

13 **Abstract:** Digital wireless telephones (commonly referred to as cellular phones) have opened up
14 vast new opportunities for electronic communication that could be of substantial benefit to
15 people with hearing loss. Unfortunately, digital cellular telephones generate electromagnetic
16 (EM) interference in hearing aids and many hearing-aid wearers cannot use these telephones. In
17 this study, experiments were performed to develop a basic understanding of this new form of
18 interference and to develop ways of predicting its effects on speech perception and the usability
19 of cellular telephones by hearing aid wearers. The results of this study benefits not only
20 consumers in selecting a hearing aid and/or cellular telephone, but also provides industry with
21 the basic theoretical underpinnings needed to allow for the development of improved wireless
22 telephones (and other digital wireless devices) that produce substantially less interference in
23 hearing aids, thereby increasing accessibility of modern digital communication systems for
24 people with hearing loss.

DRAFT GRANT/OUTPUT SUMMARY

Research Projects and Outputs Reviewed: Annual Performance Report databases that were provided to NRC and which date back to FY 2006-2007 identified eight outputs produced by this grant, five journal articles, two industry standards, and one tutorial.

The following table shows the project that was carried out under the grant, which was aimed at NIDRR's key research domain of health and function. The table also lists the outputs that correspond to the project and which were reviewed by the NRC Committee. These outputs were identified by the study's key personnel as those which would best reflect their grant's achievements.

Project	Output
A. Interference in hearing aids from digital wireless telephones: Improved predictive methods	A1. Levitt, H. 2007. Historically, the paths of hearing aids and telephones have often intertwined. <i>Hearing Journal</i> . 60(11): 20-24.
	A2. American National Standard Methods of Measurement of Compatibility Between Wireless Communications Devices and Hearing Aids

Brief Description of the Outputs:

The first output reviewed by the NRC was an invited paper (A1) stemming from The Clinical Research Summit on Hearing Aids and Wireless Technology. The purpose of the summit was to identify needs for the future development of hearing aids and wireless technology. The paper was published in a journal widely read by hearing aid engineers, telephone engineers, and

DRAFT GRANT/OUTPUT SUMMARY

1 audiologists – reaching its the intended audience and encouraging cooperation among the three
2 groups.

3

4 The second output (A2) is a Standard Method of Measurement for measuring interference in a
5 hearing aid produced by wireless communication devices, such as cellular telephones. Data,
6 methods of data analysis, and theoretical predictions developed by the project were included in
7 the standard. Standard procedures are needed for these measurements to allow researchers,
8 telephone companies, hearing aid manufacturers, and other interested groups to have a common
9 basis for comparing experimental results and for complying with regulations of the Federal
10 Communications Commission (FCC).

DRAFT GRANT/OUTPUT SUMMARY

Grant Title: Motor Training and Assessment in Adults with Hemiplegic Cerebral Palsy - The ULTrA Program

Grantee: University of Michigan

Grant Award Number: H133G050151

Grant Mechanism: Field Initiated Project

Grant Start and End Dates: December 1, 2005 to November 30, 2009

Total Direct Cost: \$446,964

Abstract: Although considered a non-progressive condition, many adults with cerebral palsy (CP) experience declines in functional performance beginning as early as late adolescence. Since our understanding and treatment of motor deficits in CP have been derived almost exclusively from pediatric populations, very little is known regarding the nature of motor declines which may occur across the lifespan.

This project proposed to implement an eight week upper limb training and assessment program (ULTrA Program) for adults with hemiplegic CP. The Motor Control Laboratory at the University of Michigan found that motor training leads to improved upper limb coordination during functional tasks in children with hemiplegic CP. These observations, based on the notion of brain plasticity, supported the view that movement training can lead to functional

DRAFT GRANT/OUTPUT SUMMARY

1 improvement despite years of limited limb use. This project targeted a growing yet neglected
2 segment of the CP community, adults, and was home-based but linked to our research laboratory
3 through the internet.
4

5 Prior to and following the intervention, a quantitative assessment of upper limb sensorimotor
6 function was made using established motor control techniques. Each participant received a
7 computer-based upper limb training unit including high speed connectivity. A 40 min
8 intervention program was performed five days a week. During three of these training sessions,
9 participants were assisted by a student coach via webcam internet connections. Data was
10 recorded and uploaded to a central website which serves as a resource for consumers and
11 researchers in the area of mobility in CP across the lifespan. Recruitment took place locally and
12 from two other areas in Michigan, thereby demonstrating increased accessibility to internet-
13 based motor training programs. This proposal addresses several future research priorities of
14 NIDRR. By targeting older individuals with CP, we directly address the issue of aging with a
15 disability. By developing an intervention program which is accessible using internet technology,
16 we address the issue of improved, cost-effective delivery of rehabilitation services and expansion
17 of evaluation approaches. Lastly, this proposal combined a community-based, theory-driven
18 model of upper limb rehabilitation with a strong education component for consumers and pre-
19 health professional students.
20

21 **Research Projects and Outputs Reviewed:** Annual Performance Report databases that were
22 provided to NRC and which date back to FY 2006-2007 identified ten outputs produced by this
23 grant, three journal articles, two working prototypes, two newsletters, one website, one

DRAFT GRANT/OUTPUT SUMMARY

intervention protocol, and one field tested product. In addition the grantee reported two journal articles to the NRC Committee.

The following table shows the two main projects that were carried out under the grant, which were aimed at NIDRR's key research domain of health and function. The table also lists the outputs that correspond to the projects and which were reviewed by the NRC Committee. These outputs were identified by the study's key personnel as those which would best reflect their grant's achievements.

Project	Output
A. Assessment of sensorimotor function in adults with hemiplegic cerebral palsy	A1. Langan, J., Doyle, S.T., Hurvitz, E.A., Brown, S.H. Influence of task on interlimb coordination in adults with cerebral palsy. Arch Phys Med Rehab 91(10) 1571-1576, 2010
	A2. S H Brown, J Langan, K L Kern, E A Hurvitz. Remote Monitoring and Quantification of Upper Limb and Hand Function in Chronic Disability Conditions. Proc. 8th Intl Conf. Disability, Virtual Reality & Associated Technologies. 31 Aug. – 2 Sept. 2010.
B. Sensorimotor Training in Adults with Hemiplegic Cerebral Palsy	B1. Brown, S.H., Lewis, C.A., McCarthy, J.M., Doyle, S.T., Hurvitz, E.A. The effects of internet-based home training on upper limb function in adults with cerebral palsy. Neurorehab Neural Repair, 6: 575-583, 2010.

Brief Description of the Outputs:

DRAFT GRANT/OUTPUT SUMMARY

1
2 The first two outputs reviewed were journal articles produced under the project aimed at
3 assessment of sensorimotor function in adults with hemiplegic cerebral palsy. Langan et al.
4 (2010) described changes in upper limb reaching performance in adults with cerebral palsy.
5 They concluded that bilateral sequential movements were more conducive to faster movement
6 time compared with unilateral and bilateral simultaneous movement. This has implications for
7 the development of more effective movement based therapies and suggests that training that
8 includes bilateral sequential movements may be beneficial to adults with hemiplegic CP. Brown
9 et al. (2010) described a home-based telerehabilitation system, Upper Limb Training and
10 Assessment (ULTrA) program, designed to improve upper limb and hand function in adults with
11 CP. The program delivered exercise modules to the patient's home and was able to transmit
12 performance related data back to the laboratory.

13
14 Under the sensorimotor training in adults with hemiplegic cerebral palsy project, the third output
15 reviewed was a journal article (B1) which described the improvement, detected through
16 increased movement speed and enhanced hand manipulation, achieved and monitored through
17 the home-based telerehabilitation system described in A2. Home-based telerehabilitation
18 programs such as ULTrA make task-based movement training more accessible to individuals
19 with disabilities while providing clinicians with quantitative feedback via remote monitoring,
20 which in turn facilitates adaptation of the training program throughout the intervention period.
21 The ability to generate and transmit quantitative measures throughout the intervention period is
22 advantageous over other rehabilitation approaches with rely on pre and post intervention
23 assessments make evaluations and changes.

DRAFT GRANT/OUTPUT SUMMARY

Grant Title: Using the US EEOC Employment Discrimination Charge Data System for
Research and Dissemination

Grant Award Number: H133G040265

Grantee: Cornell University

Grant Mechanism: Field Initiated Project

Grant Start and End Dates: October 1, 2004 to September 30, 2009

Total Direct Cost: \$450,000

Abstract: This project proposed to analyze trends in employment discrimination charges related to the ADA and other laws using data from the Equal Employment Opportunity Commission (EEOC) Charge Data System (CDS). The CDS collects data on employment discrimination charges covered under Title I of the ADA, as well as data on charges related to other laws. It contains information on: (a) the demographic characteristics of charging parties, such as gender, racial and ethnic status, age, location, and type of disability (e.g., back impairment, depression), (b) type of discriminatory behavior, such as refusal to hire, failure to provide reasonable accommodation, unfair discharge, harassment, and (c) charge outcomes, such as withdrawal with benefits, settlements, and other such outcomes. We used these data to explore trends over time and across the states, and investigated whether these trends are related to changes in the composition of the population with disabilities and changes in labor market conditions. Using

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1 regression analysis, we then explored the relationship of the ADA-related charge rates to state-
2 level economic conditions, government program participation by people with disabilities
3 statistics and other state-level characteristics. We also examined the changes in the composition
4 of charges over time with respect to the characteristics of charging party, the size and industry of
5 the employer, the type of alleged discriminatory treatment, differences between claims in the
6 EEOC and FEPA offices; differences in trends and types of charges between the ADA and other
7 statutes (specifically the ADA and ADEA); and where relevant, the potential impact of Supreme
8 Court decisions within trend changes in these compositional changes. To achieve a better
9 understanding of patterns in ADA-related charges, we sought input from and worked with the
10 EEOC and selected disability advocacy organizations, such as select state Fair Employment
11 Protection Agencies (FEPAs), state protection and advocacy agencies (P&As), and as needed the
12 American Association of Retired Persons (AARP), the American Association of Persons with
13 Disabilities (AAPD), the National Disability Rights Network (NDRN; formerly called the
14 National Association of Protection and Advocacy Systems), and the law firm of Powers, Pyles,
15 Sutter, and Verville (PPSV).

16
17 **Research Projects and Outputs Reviewed:** Annual Performance Report databases that were
18 provided to NRC and which date back to FY 2006-2007 identified four outputs produced by this
19 grant, one journal article, one technical report, one chartbook, and one website.

20
21 The following table shows the project that was carried out under the grant, which was aimed at
22 NIDRR's key research domain of employment. The table also lists the outputs that correspond to
23 the project and which were reviewed by the NRC Committee. These outputs were identified by
24 the study's key personnel as those which would best reflect their grant's achievements.

DRAFT GRANT/OUTPUT SUMMARY

1

Project	Output
A. Using the U.S. EEOC Employment Discrimination Charge Data System for Research and Dissemination	A1. Bjelland, MJ, Bruyere, SM, von Schrader, S, Houtenville, AJ, Ruiz-Quintanilla, A, Webber, DA. Age and Disability Employment Discrimination: Occupational Rehabilitation Implications. <i>J Occup Rehabil</i> 2009, online pub.
	A2. Americans with Disabilities Act (ADA) Charge Data Chartbook

2

3 Brief Description of the Outputs:

4

5 Bjelland et al. (2009) investigated the nature of employment discrimination charges that cite the
6 Americans with Disabilities Act (ADA) or Age Discrimination in Employment Act (ADEA)
7 individually or jointly. The authors found that employment discrimination charges originating
8 from older or disabled workers are concentrated within a subset of issues that include reasonable
9 accommodation, retaliation, and termination. Based on the analyses of the discrimination
10 charges filed under the ADA and ADEA, the authors discuss relevant issues to rehabilitation and
11 human resource practitioners, including strategies to improve employment outcomes of older
12 workers and those with disabilities and chronic health conditions as our labor force evolves to
13 include more members of these communities.

14

15 The second output, a chartbook (A2), was the result of a request by EEOC Office of Research,
16 Information, and Planning for a product based on ADA charges to posted on the EEOC website.

DRAFT GRANT/OUTPUT SUMMARY

- 1 The chartbook is intended to provide basic statistics on ADA charges to a wide variety of
- 2 audiences who access the EEOC website.

3

4

DRAFT GRANT/OUTPUT SUMMARY

Grant Title: Universal Access to Passenger Rail Cars

Grant Award Number: H133S050136

Grantee: LINC Design LLC

Grant Mechanism: Small Business Innovation Research project- Phase II

Grant Start and End Dates: October 1, 2005 to September 30, 2009

Total Direct Cost: \$499,750

Abstract: Since freight rail cars often share train tracks with passenger rail cars, differences in car width results in horizontal gaps between passenger rail cars and boarding platforms. The grantee proposed a compact device that can be retrofit to existing rail cars or integrated in new rail car designs. The device extends out from the rail car boarding area onto the station platform to provide quick, safe, easy and independent boarding access for all possible rail passengers. The proposed boarding device is expected to eliminate rail personnel assistance for individuals with disabilities and others with extra boarding needs when boarding and exiting trains. A motorized version of this device would increase passenger independence for all train riders and personnel; the manual version would strongly reduce personnel involvement and train delays. Support for this R&D effort has come from industry. The project builds upon Phase I activities during which the feasibility of the device was demonstrated.

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Research Projects and Outputs Reviewed: Annual Performance Report databases that were provided to NRC and which date back to FY 2006-2007 identified twelve outputs produced by this grant, two descriptive publications about the RailRamp, an Installation and User's Guide, the prototype and two subsequent versions of the RailRamp, a patent disclosure, a manual boarding ramp device, a pamphlet, an instructional brochure, and two websites on the RailRamp.

The following table shows the project that was carried out under the grant, which was aimed at NIDRR's key research domains of technology and knowledge translation. The table also lists the outputs that correspond to the project and which were reviewed by the NRC Committee. These outputs were identified by the study's key personnel as those which would best reflect their grant's achievements.

Project	Output
A. Development of a powered ramp device for use in commuter rail	A1. van Roosmalen, L. and Heiner, D. (2008). The Rail-Ramp; An Automated Bridge Plate. www.marshallelevator.com : Marshall Elevator Company.
	A2. Van Roosmalen, L., Glogowski, F.S., Heiner, D.A., Jamison, R.S., Horvath, P.D., Walker, S. (September 28, 2010). Retractable Ramp. Patent No. US 7,802,337 B2.

Brief Description of the Outputs:

Both outputs come from the ramp device project. The first output reviewed (A1) was the RailRamp Installation and User's Guide. The Guide describes the need for a rail ramp, explains

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1 how the rail ramp works, and provides the system requirements and components. Instructions are
2 provided for transporting the ramp, installing the ramp, and integrating the ramp with automated
3 doors and exiting controls. The Guide also details operation of the ramp, including deploying and
4 stowing the ramp both mechanically and manually, and provides general troubleshooting
5 instructions. Finally, the Guide describes how to maintain the ramp and provides information on
6 the testing and certification of ramp components. The Guide was intended to be used by railcar
7 manufacturers and railroad operations.

8
9 The second output reviewed (A2) was the RailRamp patent disclosure. The inventors submitted a
10 patent application on December 22, 2007. The patent provides an abstract, as well 13 figures
11 illustrating and describing the ramp from multiple perspectives, including not installed and
12 installed, and not extended and extended. Figures also show the ramp broken down into
13 components and how the components assemble together. The text of the patent contains
14 background information on the invention, including the need for a more effective ramp that is
15 also compliant with the ADA and UK Code of Practice. The patent was approved on September
16 28, 2010. The patent will allow the designer to market this device and potentially improve rail
17 car access.

DRAFT GRANT/OUTPUT SUMMARY

1 **Grant Title:** Web-enabled creation and distribution of audio-tactile maps for use in orientation
2 and mobility training
3

4 **Grant Award Number:** H133S060105
5

6 **Grantee:** Touch Graphics, Inc.
7

8 **Grant Mechanism:** Small Business Innovation Research project- Phase II
9

10 **Grant Start and End Dates:** October 1, 2006 to March 30, 2009
11

12 **Total Direct Cost:** \$499,852
13

14 **Abstract:** This Phase II SBIR project calls for the development of a system for providing one-
15 off talking tactile neighborhood maps on demand for use by individuals who are blind, have low
16 vision or are otherwise print disabled. Files downloaded from a website will be used to create
17 raised-line maps from standard Braille embossers, or using other methods. The finished maps
18 will be placed on a Talking Tactile Tablet (TTT), a computer peripheral device, and the user will
19 interact with a map by exploring it through touch sense, pressing down on streets and other
20 features to hear names and descriptions of map entities of interest to them. The system, to be
21 known as TMAP Reader, will include a web service for requesting maps of any location in the
22 US; a software application for outputting downloaded map files to a standard Braille embosser;
23 an application that facilitates user interaction with the maps; and a map production and delivery
24 service for unsophisticated users or users without access to equipment for outputting maps. Two

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stages of user testing will be carried out to evaluate the efficacy of the planned system in orientation and mobility (O&M) training.

Research Projects and Outputs Reviewed: Annual Performance Report databases that were provided to NRC and which date back to FY 2006-2007 identified eight outputs produced by this grant, three technical reports, one survey, one piece of software, one website, and two automated systems.

The following table shows the project that was carried out under the grant, which was aimed at NIDRR's key research domain of technology. The table also lists the outputs that correspond to the project and which were reviewed by the NRC Committee. These outputs were identified by the study's key personnel as those which would best reflect their grant's achievements.

Project	Output
A. Usability testing of the TMAP Reader system with up to 100 current users of the Talking Tactile Tablet in geographically diverse settings	A1. T-Map Reader Software
	A2. T-Map Production Service

Brief Description of the Outputs:

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1 Both outputs come from the TMAP project. The first output (A1) reviewed was the TMAP
2 software. The TMAP system creates dynamic, interactive maps that are accessible to users with
3 disabilities. The software works on the Talking Tactile Tablet, also developed by Touch
4 Graphics, Inc. The tactile maps used through the TMAP are intended to be explored by either
5 touch or vision. When a user presses down on a map element, the name of the element is spoken
6 aloud. According to the designer, the audio-tactile display used by the TMAP is a significant
7 improvement over previous attempts at tactile cartography and allows for much greater
8 exploration and customization of the map.

9
10 The second output (A2) reviewed was the TMAP production service. The service is an
11 automated system available through the Touch Graphics website that can generate multi-sensory
12 maps of any neighborhood
13 in the United States and Canada for use with the TMAP software. The service is very easy to use
14 and delivers maps in only a few days. According to Landua, the production service represents
15 one of the most sophisticated examples of tactile graphics production currently in the market.

DRAFT GRANT/OUTPUT SUMMARY

Grant Title: A Noninvasive Surface Electromyogram Decomposition Method and Its Application in Disability Rehabilitation

Grant Award Number: H133F070022

Grant Mechanism: Research Fellows Program

Grant Start and End Dates: October 1, 2007 to January 15, 2009

Total Direct Cost: \$75,000

Abstract³: This study developed a convenient, practical, and readily available surface electromyogram (EMG) decomposition method to replace and/or to supplement traditionally used, indwelling needle electrode-based decomposition approaches. Results benefit the rehabilitation community and a large population of patients by reducing pain, emotional tension, and risk of infection during EMG examination.

Research Projects and Outputs Reviewed: Annual Performance Report databases that were provided to NRC and which date back to FY 2006-2007 did not include information concerning this grant. The grantee reported two outputs, one journal article, and one invention, to the NRC Committee.

³ This abstract was adapted from the project abstract found on naric.com.

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The following table shows the project that was carried out under the grant, which was aimed at NIDRR's key research domain of health and function. The table also lists the outputs that correspond to the project and which were reviewed by the NRC Committee. These outputs were identified by the study's key personnel as those which would best reflect their grant's achievements.

Project	Output
A. A Noninvasive Surface Electromyogram Decomposition Method and Its Application in Disability Rehabilitation.	A1. Zhou P, Suresh NL, Lowery MM, Rymer WZ. (2009). Nonlinear spatial filtering of multichannel surface electromyogram signals during low force contractions. IEEE Trans Biomed Eng. 2009 Jul; 56(7): 1871-9.
	A2. Selective surface electrode arrays

Brief Description of the Outputs:

Zhou et al. (2009) introduced the use of nonlinear spatial filters to identify single motor unit discharge from multiple channel surface electromyogram (EMG) signals during low force contractions. Previously, invasive percutaneous intramuscular EMG recordings were routinely used to selectively record single motor unit activity. This article investigated the advantages of nonlinear spatial filtering for the enhancement of surface motor unit action potentials using noninvasive surface EMG recordings. Previous methods relied upon linear methods for filtering but the authors demonstrate that nonlinear spatial filtering achieves better results for single motor unit detection during low force contractions.

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1

2 The second output (A2) reviewed was a 1- and 2- dimensional surface electrode array developed
3 for noninvasive motor unit activity recording. The design allows for the extraction of single
4 motor unit information using surface EMG and the appropriate signal processing methods
5 described in output A1.

DRAFT GRANT/OUTPUT SUMMARY

Grant Title: Demographic Soup: Disentangling the Conceptual, Political, and Methodological Dimensions of Disability Statistics

Grant Award Number: H133F060011

Grant Mechanism: Research Fellows Program

Grant Start and End Dates: December 1, 2006 to November 30, 2009

Total Direct Cost: \$75,000

Abstract: There are wide variations in disability research including how disability is defined and how information on the various definitions is obtained and converted into useable data. This project brings together, in one document, the accumulation of knowledge on defining and measuring disability in survey and census contexts. Through the incorporation of several methodologies including 1) historical review, 2) analysis of political processes and decision-making, and 3) complete examination of the source, placement, and evaluation of disability measures currently in use, this book manuscript contributes to the improvement of disability statistics and serves as a reference document to understanding the data that exists. The book manuscript is divided into five sections: 1) examination of the political and historical context, which includes chapters on the history of disability measurement; 2) examination of the conceptualization and definition of disability, including chapters on the political definitions for programmatic purposes and theoretical definitions and models; 3) examination of the science, purpose, and relationships between the components of measurement, and the special problems

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with measurement in relation to specific populations (i.e. children, elderly); 4) reviews of samples of research analyses focused on the use of data, including sources of data, research questions, and with special focus on measures used in specific areas of research (i.e. aging and employment); and 5) exploration of international measurement of disability and the role of the US in its development. Conclusions include recommendations for improving and standardizing the measurement and data collection process.

Research Projects and Outputs Reviewed: Annual Performance Report databases that were provided to NRC and which date back to FY 2006-2007 identified four outputs produced by this grant, one journal article, one technical report, and one book chapter, and one set of presentations.

The following table shows the project that was carried out under the grant, which was aimed at NIDRR's key research domains of demographics and knowledge translation. The table also lists the outputs that correspond to the project and which were reviewed by the NRC Committee. These outputs were identified by the study's key personnel as those which would best reflect their grant's achievements.

Project	Output
A. Demographic Soup:	A1. Disability and Health in the United States, 2001-2005
Disentangling the Conceptual, Political, and Methodological Dimensions	A2. Population Survey Measures of functioning: Strengths and Weaknesses

DRAFT GRANT/OUTPUT SUMMARY

of Disability Statistics	
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Brief Description of the Outputs:

The first output reviewed by the NRC was a chartbook (A1) compiled using data from the National Health Interview Survey to begin to uncover what the data represents and what it tells us about health care for persons with disabilities. To this end, the first part interprets current disability definitional approaches and translates them into measures that are available in the National Survey. The rest of the chartbook uses those measures to examine the health care experience of persons with disabilities.

The second output reviewed was an appendix for an NRC Workshop Summary (A2), Improving the Measurement of Late-Life Disability in Population Surveys: Beyond ADLs and IADLs. It discusses the measurement process, the components of measurements, and breaks down the process into steps one should consider when measuring or choosing measurements that are already constructed.

DRAFT GRANT/OUTPUT SUMMARY

Grant Title: Physical and Social Environmental Factors that Influence Health and Participation Outcomes for Chronically-Ill Adults

Grant Award Number: H133F080014

Grant Mechanism: Switzer

Grant Start and End Dates: July 1, 2008 to June 30, 2009

Total Direct Cost: \$65,000

Abstract: This project explored the factors of health and participation outcomes among older adults with chronic conditions who are living in the community with or without disabilities. Considering individual factors such as informal, formal, and societal supports, there were three research objectives: (1) determining the direct and indirect effect of social capital in a community on health and participation outcomes; (2) identifying the relationship between health and participation outcomes with measures of the neighborhood; and (3) assessing the relationship of the subjective measure of perceived social capital and the objective measures of the neighborhood for their collective influence on the health and community participation of older adults with and without disabilities. The project developed research aimed to improve community practice, policy, and the health system in order to assist adults in achieving independence, greater participation, and social involvement.

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Research Projects and Outputs Reviewed: Annual Performance Report databases that were provided to NRC and which date back to FY 2006-2007 did not include information on this grant. The grantee reported two outputs, one journal article and one abstract, to the NRC Committee.

The following table shows the project that was carried out under the grant. The project was aimed at NIDRR's key research domain of participation and community living. The table also lists the outputs that correspond to the project and which were reviewed by the NRC Committee. These outputs were identified by the study's key personnel as those which would best reflect their grant's achievements..

Project	Output
A. Physical and Social Environmental Factors that Influence Health and Participation Outcomes for Chronically Ill Older Adults	A1. Prvu Bettger JA. System of support and services and the relationship with hospital utilization. Submitted for Publication. Under Review - Revision. 2010
	A2. Prvu Bettger JA. What aspects of the social environment are associated with physical activity post-stroke? International Stroke Conference 2010, February 25, 2010, San Antonio, TX. Published in: Stroke, April 2010 in Stroke 41(4) page e355 (abstract p397)

Brief Description of the Outputs:

Both outputs came from the project concerning chronically ill older adults. The first output (A1) reviewed was a journal article on a study of hospital utilization among 2,286 non-working adults

DRAFT GRANT/OUTPUT SUMMARY

1 aged 60 or greater reporting at least one chronic condition or condition requiring regular medical
2 treatment in the 2006 Southeastern Pennsylvania Household Health Survey. Several person-level
3 factors were found to be strongly associated with hospital utilization, such as older age, low-
4 income, poor-fair perception of health, and use of an assistive device. Social environment factors
5 found to be significantly associated with hospital utilization were receipt of formal care, receipt
6 of meal services, and absence of a regular source of care. Findings highlight the relationship
7 between specific social supports and services and hospital utilization, but further investigation is
8 needed into the interaction of social factors and the effects on hospital utilization.

9
10 The second output (A2) was an abstract from a study of stroke survivors' activity and factors that
11 prevent them from being physically active. Prvu-Bettger analyzed the responses of 214 stroke
12 survivors who participated in the 2004 Southeastern Pennsylvania Household Health Survey.
13 Absence of depression, good-excellent health status, community participation, and use of
14 transportation services were positively correlated with physical activity. Findings highlight the
15 need for social environment supports to facilitate physical activity post-stroke, and for greater
16 attention to environmental influence on health behavior in health promotion research and
17 practice.

Appendix B

Rating Sheets/Questionnaires

1. Process Evaluation Measures:
 - a. Questionnaire for NIDRR Stakeholders
 - b. Questionnaire for NIDRR Peer Reviewers
2. Summative Evaluation Measures:
 - a. Grantee Invitation Letter
 - b. Informed Consent Form
 - c. Grantee Questionnaire
 - d. Review Procedures for Summative Evaluation
 - e. Rating Sheet of the Quality of the Outputs

App-B-1a External Evaluation of the National Institute on Disability and Rehabilitation Research (NIDRR) and its Grantees

Web-based Questionnaire for NIDRR Stakeholders

INFORMED CONSENT FORM

What the study is about: An expert committee of the National Research Council, of The National Academies, in Washington, DC is conducting an evaluation of some of the activities of the National Institute on Disability and Rehabilitation Research (NIDRR). The committee will be (1) reviewing NIDRR's priority setting and peer review processes; and (2) reviewing the quality of grantee "outputs" for a sample of NIDRR grants. ["Peer review" refers to a process in which experts review grant applications and make recommendations about whether they should be funded. "Outputs" are publications, measures, intervention protocols, devices, and information resources that are produced as part of a grant.]

What we will ask you to do: We are inviting you to take part in the first part of the evaluation—specifically, the review of NIDRR's priority setting processes. We will ask you a set of questions to help us understand these processes and how they may affect NIDRR's work. The questionnaire will take about 15 to 20 minutes to complete. Your participation is completely voluntary. You can choose not to answer some of the questions or to stop at any point, and there will be no consequences.

Benefits and risks:

Benefits: By taking part in the evaluation you will provide information that may help NIDRR improve its research portfolio for the benefit of persons with disabilities.

Risks and protections: You might be concerned that the information you share will not be kept private. However, we want to assure you that all of your comments will be kept confidential. Study results will be presented only in combined form, with no individual person or organization being identified. Your name will not be attached to your answers. A research identification number will be used instead. The Study Director will keep a list linking your name with your number. This list, along with the data collected, will be stored securely at the National Research Council. Only the study personnel will have access to the master list, and only for research purposes.

Compensation: There is no compensation for taking part in the evaluation.

If you have any questions: Please contact the Senior Program Officer, Dr. Jeanne Rivard, if you have any questions about this consent form or the study. She can be contacted by phone at: 202-334-2967, or by email at: jrivard@nas.edu.

If you have any questions, comments, or concerns about taking part in this study, first contact Dr. Rivard. If for any reason you do not want to contact her, or you still have concerns after doing so, you may contact the Institutional Review Board (IRB) of the National Academy of Sciences (NAS), which reviewed and approved the study plans and this consent form. You can reach the chair of the IRB, Ronald D. Taylor, Human Protections Administrator, by telephone at 202-334-1659 or you may write to him at the National Academy of Sciences; Room 1026; 500 Fifth Street, NW; Washington, DC 20001.

1 **Statement of Consent:**
2

- ☐ I have read the above information, understand it, and agree to take part in the study.
3 ☐ I do not agree to take part in the study.

Web-based Questionnaire for NIDRR Stakeholders

Please respond as a representative of your organization so that your answers will reflect how your organization relates to NIDRR.

1. Although your organization has multiple functions, select from the list below the one type that most closely matches your own organization.

- ☐ Professional association
- ☐ Advocacy organization
- ☐ Service provider
- ☐ Funder of research and/or development grants
- ☐ Technical assistance and dissemination
- ☐ Commercial manufacturer/distributor
- ☐ Other (Please specify) _____

2. To what extent is your organization familiar with the National Institute on Disability and Rehabilitation Research (NIDRR)?

1	2	3	4	5	14
☐	☐	☐	☐	☐	15
Not at all		Somewhat		Very much	16
					17

3. Please check all of the ways in which your organization has interacted with NIDRR since January 1, 2005.

Information Exchange

- ☐ Have used NIDRR website or related information sources to search for information, tools, or resources for working with consumers (non grant information)
- ☐ Have used NIDRR website or related resources to search for information about grants
- ☐ Have spoken with NIDRR staff in person or on the phone about specific professional issues
- ☐ Have attended NIDRR trainings, workshops, or conferences
- ☐ Other (Please specify in box below)

Funding

- ☐ Have received funding from NIDRR for research & development grants
- ☐ Have received funding from NIDRR for training, knowledge transfer, or dissemination grants
- ☐ Have received funding from NIDRR for activities other than grants (e.g., contract or agreements to conduct an evaluation, provide expert consultation, or write a paper, etc.)
- ☐ Have applied for funding, but did not receive award
- ☐ Other (Please specify in box below)

1
2 Collaboration

- ☐ Have collaborated with NIDRR as a member of a consortium or professional association
☐ Have participated in general planning and special purpose meetings convened by NIDRR
☐ Have coordinated activities to support joint priorities and/or to avoid duplication
☐ Other (Please specify in box below)

☐ Have not interacted with NIDRR on any of the above types of information, funding, or collaboration activities.

3
4 **4. Please use the space below to comment on the above, or any other types of**
5 **interactions, your organization has had with NIDRR.** (Click in the upper left-hand corner
6 to enter text.)
7

8
9 **5. Has your organization had opportunities to review and comment on NIDRR's long**
10 **range plan or funding priorities?**
11

- ☐ Yes
☐ No
☐ Don't know

12
13 **6. How did your organization find out about opportunities to review and comment on**
14 **NIDRR's long range plan or funding priorities?**
15

- ☐ Federal Register
☐ Professional list serve
☐ University grants source
☐ Professional newspaper
☐ Personal invitation to our organization from NIDRR
☐ Other (please specify): _____
☐ Don't know

16
17 **7. Since January 1, 2005 has anyone from your organization submitted comments to**
18 **NIDRR about its long-range plan?**
19

- ☐ Yes
☐ No
☐ Don't know

8. Since January 1, 2005 has anyone from your organization submitted comments to NIDRR about its specific funding priorities (e.g., grant announcements) published in the Federal Register?

- ☐ Yes
☐ No
☐ Don't know

9. In your opinion, to what extent are NIDRR's long range planning and priority setting processes (Please check the boxes beneath the responses—select only one per row):

	Not at all		Somewhat		Very Much	Don't know
Transparent	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	☐
Publicized	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	☐
Relevant to your organization	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	☐
Responsive to emerging issues in disability rehabilitation and research	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	☐
Welcoming of stakeholder feedback	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	☐
Responsive to stakeholder feedback	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	☐

10. In your opinion, how do NIDRR's long range planning and priority setting processes compare with those of other federal research agencies?

- ☐ NIDRR's processes are weaker than other agencies'.
☐ NIDRR's processes are about the same as other agencies'.
☐ NIDRR's processes are stronger than other agencies'.
☐ Don't know

11. How well are the grants that NIDRR funds advancing the field in a direction that is beneficial for your organization, and the members and consumers that you represent? (Please select only one response.)

1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	☐	☐
Not at all		Somewhat		Very much	Don't know	Not Applicable

1
2
3
4 **12. What types of grants have served your organization, and the members and**
5 **consumers that you represent?** (Click in the upper left-hand corner to enter text.)
6
7

8
9
10
11 **13. To what extent are the products of the grants that NIDRR funds (e.g., publications,**
12 **websites, training or training materials, tools, devices, measures, interventions, etc.)**
13 **used by your organization? (Please select one response.)**

1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	☐	☐
Not at all		Somewhat		Very much	Don't know	Not Applicable

14
15 **14. What are the three most important NIDRR-funded products used by your**
16 **organization?** (Click in the upper left-hand corner to enter text.)
17
18

19
20
21
22
23 **15. What three things might NIDRR do to enhance its long range planning and priority**
24 **setting processes?** (Click in the upper left-hand corner to enter text.)
25
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Thank you very much for taking the time to complete this questionnaire. We may be contacting some respondents later to ask additional questions. If you would be willing to take part in brief follow-up interviews, please check here.

☐ Yes, it's okay to contact me.

☐ No, thank you. I'm finished!

12
13
14

Contact Information

(Click on the leftmost portion of the line to enter text.)

e-mail address: _____

Phone number: _____

15
16

**App-B-1b External Evaluation of the National Institute on Disability and Rehabilitation
Research (NIDRR) and Its Grantees**

Web-based Questionnaire for NIDRR Peer Reviewers

INFORMED CONSENT FORM

What the study is about: An expert committee of the National Research Council, of the National Academies, in Washington, DC is conducting an evaluation of some of the activities of the National Institute on Disability and Rehabilitation Research (NIDRR). The committee will be (1) reviewing NIDRR's priority setting and peer review processes; and (2) reviewing the quality of grantee "outputs" for a sample of NIDRR grants. ["Peer review" refers to a process in which experts review grant applications and make recommendations about whether they should be funded. "Outputs" are publications, measures, intervention protocols, devices, and information resources that are produced as part of a grant.]

What we will ask you to do: We are inviting you to take part in the first part of the evaluation—specifically, the review of NIDRR's peer review processes. We will ask you a set of questions to help us understand these processes and how they may affect NIDRR's work. The questionnaire will take about 15 to 20 minutes to complete. Your participation is completely voluntary. You can choose not to answer some of the questions or to stop at any point, and there will be no consequences.

Benefits and risks:

Benefits: By taking part in the evaluation you will provide information that may help NIDRR improve its research portfolio for the benefit of persons with disabilities.

Risks and protections: You might be concerned that the information you share will not be kept private. However, we want to assure you that all of your comments will be kept confidential. Study results will be presented only in combined form, with no individual person or organization being identified. Your name will not be attached to your answers. A research identification number will be used instead. The Study Director will keep a list linking your name with your number. This list, along with the data collected, will be stored securely at the National Research Council. Only the study personnel will have access to the master list, and only for research purposes.

Compensation: There is no compensation for taking part in the evaluation.

If you have any questions: Please contact the Senior Program Officer, Dr. Jeanne Rivard, if you have any questions about this consent form or the study. She can be contacted by phone at: 202-334-2967, or by email at: jrivard@nas.edu.

If you have any questions, comments, or concerns about taking part in this study, first contact Dr. Rivard. If for any reason you do not want to contact her, or you still have concerns after doing so, you may contact the Institutional Review Board (IRB) of the National Academy of Sciences (NAS), which reviewed and approved the study plans and this consent form. You can reach the chair of the IRB, Ronald D. Taylor, Human Protections Administrator, by telephone at 202-334-1659 or you may write to him at the National Academy of Sciences; Room 1026; 500 Fifth Street, NW; Washington, DC 20001.

1 **Statement of Consent:**

☐ I have read the above information, understand it, and agree to take part in the study.

☐ I do not agree to take part in the study.

2

Web-based Questionnaire for NIDRR Peer Reviewers

1. On how many NIDRR peer review panels have you served since January 1, 2005?
(Please state the total number, such as 0, 1, 2, 3, 4, etc.): _____

(By panel, we mean every time a group of peer reviewers is convened to conduct a review, not just membership on a given panel.)

2. Across the following program funding mechanisms, please check all of those for which you have reviewed applications since January 1, 2005 (See NIDRR website for a description of these mechanisms)

Disability and Rehabilitation Research Projects (DRRP) – General	☐
Disability Business Technical Assistance Centers (DBTAC)	☐
Traumatic Brain Injury Model Systems Centers	☐
Burn Model Systems Centers	☐
Spinal Cord Injury Model Systems Centers	☐
Rehabilitation Research and Training Centers (RRTCs)	☐
Rehabilitation Engineering Research Centers (RERCs)	☐
Field Initiated Projects – Research Grants	☐
Field Initiated Projects – Development Grants	☐
Small Business Innovation Research (SBIR) – Phase I	☐
Small Business Innovation Research (SBIR) – Phase II	☐
DRRP - Knowledge Translation	☐
DRRP – Section 21	☐
(Switzer) Research Fellowship Program	☐
Advanced Rehabilitation Research Training Projects	☐
Don't Remember	☐

3. In your experience, how would you rate the following aspects of the NIDRR peer review processes (Please check the boxes beneath the responses—select only one per row):

	Poor		Adequate		Excellent	DON'T KNOW	NOT APPLICABLE
Quality of the training to prepare you for the review	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	☐	☐
Adequacy of time for review of materials before the meeting	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	☐	☐
Level of expertise of the peer review panel members	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	☐	☐
Appropriateness of the evaluation criteria to applications under review	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	☐	☐
Clarity of the criteria when applying them to applications	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	☐	☐

	Poor		Adequate		Excellent	DON'T KNOW	NOT APPLI- CABLE
Appropriateness of scoring system to applications under review	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	☐	☐
Ease of applying scoring system to applications	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	☐	☐
Thoroughness of the deliberation (i.e., grant scoring and discussion) during the meeting.	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	☐	☐
Use of reviewers' time during the panel meeting	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	☐	☐
Support and facilitation of the review panel by NIDRR staff	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	☐	☐
Guidance in writing your reviewer comments	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	☐	☐
Integrity of the peer review process overall	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	☐	☐
Consistency in the overall quality of the peer reviews across panels (if you have served on three or more panels).	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	☐	☐

4. Any additional comments you may have on these aspects of NIDRR's peer review processes would be useful. Please use the space below. (Click in the upper left-hand corner to enter text.)

5. How has the overall quality of NIDRR's peer review processes changed since January 1 2005 (if you have served on different panels over time)?

- ☐ Quality has decreased.
☐ Quality is about the same.
☐ Quality has increased.
☐ Don't know
☐ Not applicable

6. Typically, the number of applications you received for each NIDRR review panel was:

- ☐ More than you would like to review.
☐ About the right number.
☐ Fewer than you would like to review.

7. Typically, the amount of time you spent on each NIDRR review panel was:

- ☐ More time than you would like to spend.
☐ About the right amount.
☐ Less time than you would like to spend.

8. Have you participated in NIDRR peer reviews that were convened through:

	Yes	No
In-person meetings?	☐	☐
Teleconference?	☐	☐

9. In your opinion, how did the quality of a NIDRR peer review compare when conducted in person versus teleconference?

- ☐ Quality of peer reviews is better in in-person meetings.
☐ Quality of peer reviews is better in teleconference meetings.
☐ Quality of peer reviews via in-person meetings or teleconference is about the same.
☐ Don't know
☐ Not applicable

10. Have you served as a peer reviewer of proposals for federal agencies other than NIDRR since January 1, 2005?

- ☐ Yes
☐ No

11. How would you compare the following characteristics of NIDRR peer reviews with those of other federal agencies? (Please check the boxes beneath the responses—select only one per row.)

	NIDRR's are much weaker than other agencies		About the same		NIDRR's are much stronger than other agencies	Don't Know	Not Appli- cable
Expertise of the panel members	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	☐	☐
Quality of the proposals reviewed	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	☐	☐
Quality of the review process	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	☐	☐
Transparency of the review process	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	☐	☐
Fairness of the review process	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	☐	☐
Reliability of the ratings	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	☐	☐

1
2
3 **12. What three things would you suggest to enhance NIDRR's peer review processes?**
4 (Click in the upper left-hand corner to enter text.)
5
6

7
8
9
10 **Thank you very much for taking the time to complete this questionnaire. We may be**
11 **contacting some respondents later to ask additional questions. If you would be willing**
12 **to take part in brief follow-up interviews, please check here.**
13

☐ **Yes, it's okay to contact me.**

☐ **No, thank you. I'm finished!**

14
15 **Contact Information**

16 (Click on the leftmost portion of the line to enter text.)
17

e-mail address: _____
Phone number: _____

App-B-2a

THE NATIONAL ACADEMIES

Advisers to the Nation on Science, Engineering, and Medicine

Division of Behavioral and Social Sciences and Education
Committee on Human-Systems Integration

500 Fifth Street, NW
Washington, DC 20001
Phone: 202 334 2678
Fax: 202 334 2210
Email: cohsi@nas.edu
www.nationalacademies.org

October 6, 2010

Grantee Address

Dear Dr. _____:

Last week we sent you an email to inform you that you are being invited to participate in the External Evaluation of the National Institute on Disability and Rehabilitation Research (NIDRR) and its Grantees that is being conducted by an expert committee of the National Research Council of the National Academies. This independent evaluation is being sponsored by NIDRR for the purpose of: 1) assessing NIDRR's priority setting and peer review processes and 2) reviewing the quality of grantee outputs for a sample of grants that represent the NIDRR portfolio.

Your NIDRR-funded grant (Grant # _____, Grant Title: _____) was selected to be reviewed as part of the evaluation of grantee outputs. However, your participation is completely voluntary. If you do agree to be part of the evaluation, your participation will involve the following activities.

1. We will ask you to nominate two outputs that were produced under each project that was funded by the grant. These will be outputs that best reflect your grant's achievements. We are using the four NIDRR categories of outputs as defined in NIDRR's Annual Performance Report (APR), which include a) Publications; b) Tools, Measures, and Intervention Protocols; c) Technology Products and Devices; and d) Informational Products. The committee will assess the quality of the outputs which you identify using criteria of technical quality, the extent to which they advance knowledge, their potential impact, and their dissemination.
2. To conduct the review, we would like to examine the actual outputs and to review any documentation that you may have about the outputs.
3. We will ask you to complete a questionnaire about each output that asks you to briefly summarize evidence of their technical quality, how they advance knowledge, their potential impact, and how they were disseminated.
4. The questionnaire will also ask you to respond to a brief set of questions at the grant level about approaches you used in managing your grant, how the grant may have generated

new research and projects, and about your perspectives of key NIDRR processes which may influence grant results.

5. We may also ask you to participate in a follow-up telephone or videoconference interview. If so, we would like to audio-record the discussion between you and the committee.

The attachments that follow this letter include, first, an informed consent form that explains what we will do with the results of the evaluation and what steps we will take to protect the confidentiality of the evaluation results specific to your grant. The second attachment is the Grantee Questionnaire referred to above that provides instructions for:

- identifying outputs to be reviewed,
- completing the supplemental questions for each output, and
- sending us your signed consent forms, your outputs, and your completed questionnaire.

Please note that we are sending this package to you in electronic and hard copy form.

We hope that you will decide to participate. If you have any questions please don't hesitate to contact one of us using the information below.

Sincerely,

Jeanne Rivard, Ph.D., Co-Study Director
The National Academies
National Research Council
500 Fifth Street, NW
Washington, DC 20001
Phone: 202-334-2967
Email: jrivard@nas.edu

Mary Ellen O'Connell, Co-Study Director
The National Academies
National Research Council
500 Fifth Street, NW
Washington, DC 20001
Phone: 202-334-2607
Email: moconnell@nas.edu

**App-B-2b External Evaluation of the National Institute on Disability and Rehabilitation Research
(NIDRR) and Its Grantees**

INFORMED CONSENT FORM
(For NIDRR Grantees)

What the study is about: An expert committee of the National Research Council of the National Academies, in Washington, DC is developing an evaluation framework that will be used to: 1) review NIDRR's priority setting and peer review processes; and 2) review the quality of grantee "outputs" for a sample of grants that represent the NIDRR portfolio. ["Peer review" refers to a process in which experts review the merits of a grant application in considering whether it should be funded. "Outputs" are publications, measures, intervention protocols, devices, or information resources that are produced as part of a grant.] The committee will also assess the design and implementation of the evaluation process and make recommendations for additional evaluation cycles that may be performed subsequent to this effort.

What we will ask you to do: We would like to invite you to participate in the evaluation.

Your participation will involve:

1. Having outputs produced under your grant peer reviewed through a quality assessment by an expert panel.
2. To conduct the review, we would like to examine a copy of the actual outputs and to review any documentation that you may have about the outputs.
3. We will ask you to complete a questionnaire about the outputs to assist in assessing their technical quality, the extent to which they advance knowledge, their potential impact, and if applicable, their dissemination.
4. We may ask you to participate in a follow-up telephone or videoconference interview where we would audio-record the discussion between you and the committee.
5. We will also ask you to respond to a brief set of questions at the grant level about your grant management, the generation of new research and projects, and about key NIDRR processes which may influence grant results.

Taking part is voluntary. Your participation is completely voluntary. You can chose not to answer some of the questions, and there will be no consequences.

Benefits and risks:

Benefits: By taking part in the evaluation you will provide information that may help NIDRR improve its research portfolio for the benefit of persons with disabilities.

Risks: Because NIDRR has funded some of your research and development activities, you may feel uncomfortable having your grant's outputs formally rated in the study, or in sharing your opinions and perspectives on NIDRR's key management processes. You might feel that this could be a risk to your future grant funding. We want you to know, however, that we will take every step necessary to protect your confidentiality and minimize this risk.

Your answers will be confidential. In the final evaluation report, we will briefly describe your grant and the outputs that were reviewed, by their titles and grantee institutions. Your name as the Principal Investigator, or other investigators on your team, will not be used. In most cases we expect that you have

1 already placed information about the outputs in the public domain through publications, presentations at
2 conferences, and through NIDRR's National Rehabilitation Information Center (NARIC) website.

3
4 However, distinct from these descriptions will be your responses on the Grantee Questionnaire and the
5 committee's quality ratings of your outputs. For analysis and reporting, these narrative and quantitative
6 data will be de-identified and aggregated across all outputs and all grants. A research identification
7 number will be used to track grants and their specific outputs. Outputs may be analyzed by categories,
8 such as output type (e.g., publications, tools, technology, information products); quality criteria assessed
9 (e.g., technical quality, knowledge advancement, potential impact); or program funding type (e.g., center
10 grant, field initiated grant, training grant, etc.). If your grant or your output represents one of a kind and
11 there is a risk of identifying you because of this, your data will be aggregated with another larger group
12 where identification will not be a risk.

13
14 Every effort will be made to protect the confidentiality of the information that you provide. The Study
15 Director will keep a list linking the grant and output research ID numbers with that output's identifying
16 information (institution, grant title). This list, along with the data collected, will be stored securely at the
17 National Research Council, and will be accessible only by the Study personnel. If a telephone or
18 videoconference interview is convened to gather additional follow-up information, the transcription of
19 audio-recorded interviews will be combined in a dataset with the interviews of all of the other
20 respondents, then analyzed for common themes across the interviews. The audiotapes, transcriptions,
21 grantee questionnaires, committee ratings, and other raw data collected will be destroyed at the end of the
22 study when the report is released.

23
24 **Compensation:** There is no compensation for participating in the evaluation.

25
26 **If you have any questions:** The Co-Study Director of the evaluation and contact for questions is Jeanne
27 Rivard, Ph.D. If you have any questions about this consent form or the study, she can be contacted by
28 phone at: 202-334-2697, or by email at: jrivard@nas.edu.

29
30 If you have any questions, comments, or concerns about taking part in this study, first talk to Dr. Rivard
31 above. If for any reason you do not want to do this, or you still have concerns after doing so, you may
32 contact the Institutional Review Board (IRB) of the National Academy of Sciences (NAS), which
33 reviewed and approved the study plans and this consent form. You can reach the chair of the IRB by
34 contacting Ronald D. Taylor, Human Protections Administrator, by telephone at 202-334-1659 or you
35 may write to him at the National Academy of Sciences; Room 1026; 500 Fifth Street, NW; Washington,
36 DC 20001.

37
38 **Statement of Consent:** I have read the above information, and have received answers to any questions I
39 asked. I consent to take parting in the study.

40
41 Your Signature _____ Date ____ - ____ - ____

42
43 Your Name (printed) _____

44
45
46 In addition to agreeing to participate, if there is a follow-up interview, I also consent to having it tape-
47 recorded.

48
49 Your Signature _____ Date ____ - ____ - ____

App-B -2c External Evaluation of the National Institute on Disability and Rehabilitation Research (NIDRR) and its Grantees

SUMMATIVE EVALUATION: GRANTEE QUESTIONNAIRE

Grant Award Number:

Grant Title:

Grantee:

Program Mechanism:

Grant End Date:

INSTRUCTIONS TO GRANTEES

This questionnaire has been designed to obtain information to assist the Committee in assessing the quality of your grant's outputs. NIDRR has provided to the Committee and the National Research Council (NRC) staff copies of its Annual Performance Report (APR) database and your last APR and your final APR. As you will see in certain places on the questionnaire we have inserted information from your APR to facilitate your completion of the questionnaire (e.g., Table 1 lists your research and development projects, and Table 2 lists your outputs reported in the APR). Where this information is in error, we would appreciate your pointing the errors out to us and correcting it; and/or updating the information as needed.

The questionnaire is divided into the following three parts:

Part A. Nominating Outputs for Review. This section asks you to nominate, for the Committee's review, the "top 2" outputs for each of your projects that best reflect your grant's achievements (Table 1 below). The Committee would prefer to review one publication and one other type of output for each project. However if you only have publications, please nominate these as your "top 2".

To make this process easier, the NRC staff has populated a list of the outputs (Table 2 below) that were reported for your grant in the APR. You could select the top 2 outputs from this table. However you are not constrained to select from this list if there are other outputs that you think better reflect your grant's achievements.

For Committee review we are requesting materials and information regarding the actual outputs selected as the top 2 for each project.

- For publications, the material for review would be pdf copies of each article.
- For the other outputs, materials for review would include:

- Electronic or hard copies of the measures, tools, intervention protocols, manuals; or links to websites, pictures or other graphic representations of tools or devices that have been produced.
- An abstract or summary of each output, which briefly describes:
 - what the output is,
 - its purpose,
 - target audience,
 - methods, and
 - how the output fits into the overall goals and objectives of the project and grant

Part B. Additional Questions about Outputs. For each of the outputs you nominated for review, the Committee has a series of questions related to their technical quality, how they may have advanced knowledge, their potential impact, and their dissemination. We ask that you complete the Part B section for each output. If the answers to certain questions would be the same across different outputs, you can note this and cut and paste responses from earlier output forms to other ones. Please make your responses brief, but as specific and quantitative as possible.

Part C. Grant-level Questions. The questionnaire will also contain a few other items asking about how you managed your grants to produce the highest quality outputs, how your grant's results may have generated new projects, and how key NIDRR processes influence results.

Your complete package of materials will contain:

- Your signed informed consent form
- Copies of your publications and other outputs (e.g., measures, tools, intervention protocols, manuals, links to websites, pictures or other graphic representations of devices that have been produced)
- Your completed Grantee Questionnaire

Please send these materials by DATE to:

Matt McDonough
The National Academies
National Research Council
500 Fifth Street, NW
WS 1134
Washington, DC 20001

We are enclosing an addressed Fedex form that can be used when mailing your package of materials to us. We estimated a shipment cost that would cover a weight up to 10 lbs. (e.g., for large center grants or devices). If your package weighs more than this, Fedex will charge us the correct amount.

If your package is light and you want to send it electronically, you could email it to Matt at mmcdonough@nas.edu. However, you would need to scan your signed consent form, and send that in a pdf document.

Part A. Nominating Outputs for Review

When referring to "outputs", we are using the four NIDRR categories of outputs as defined in NIDRR's Annual Performance Report, which include: a) Publications; b) Tools, Measures, and Intervention Protocols; c) Technology Products and Devices; and d) Informational Products.

Per the instructions for nominating outputs for review, please record your nominations for your "top 2" outputs for each of your projects in Table 1 below. (Reminder "top 2" refers to those that best reflect your grant's achievements). As you can see the NRC staff has already populated Table 1 with the names of your research and development projects from data in the APR. Table 2, which follows, contains a list of outputs from which you can cut and paste into Table 1 below. Please identify any errors in this information that we have provided from your APR and correct it as needed.

Table 1. Projects and Nominated Outputs

#	Names of R & D Projects in Grant	Names of Top 2 Outputs for each Project <i>Outputs to be inserted by grantee from Table 2 below or add others as needed</i>
Research Projects		
R1		1. 2.
Development Projects		
D1	Dissemination	1. 2.

INSERT GRANTEES' PROJECTS TABLE HERE

The table below lists all of the publications and other outputs that were listed in the APR data provided by NIDRR. Please use this table below in selecting your top 2 outputs for each project. (You can cut and paste from Table 2 into Table 1.) However you are not constrained to select only from this list if there are other outputs that you think better reflect your grant's achievements.

Table 2. List of Outputs from APR

Type of Output	Title of Output
publications	(title)
tool	(title)

Part B. Additional Questions about Outputs

Please use one copy of this form for each publication and each other output for the "top 2" outputs that you selected for each project in Part A above, and provide the following information. Please make your responses brief, but as specific and quantitative as possible. If you consider the criterion not to be applicable to your output, please explain. (Please note that an electronic copy of the questionnaire was included in the email version of this package.)

Name of Output: _____

B1. Technical Quality of Output

In the space below, please describe examples of the technical quality of your output, such as:

- The particular approach or methodology used in developing your output
- Relevant peer recognition such as peer reviews or evaluations, peer endorsements, invitations to present at professional forums or conferences, invitations to present testimony, receipt of awards or honors, etc.
- Receipt of a patent, FDA approval, or use of your output in standards development
- Evidence of the usability and accessibility of the output

B2. Advancement of Knowledge

Please use the space below to describe how this output has advanced knowledge. To structure your response, include points such as:

- What the importance of your original question or issue was
- How the output has advanced knowledge in arenas, such as:
 - making discoveries
 - providing new information
 - establishing theories, measures, and methods
 - closing gaps in the knowledge base
 - developing new interventions, products, technology, and environmental adaptations

B3. Potential Impact

In the space below, please briefly describe evidence of your outputs' potential (or actual) impact on the following audiences, as relevant to your output:

- Science (e.g., new areas of inquiry, methodology, etc.)
- People with disabilities: health, quality of life, participation
- Provider practice
- Health and social systems
- Social and health policy
- Private sector/commercialization
- Capacity building in the field of rehabilitation and disability research and development (e.g., scientists, graduate students, etc.)
- Other

Include information about how this potential impact was tested, and what the results were.

B4. Dissemination of Outputs

In the space below please provide evidence of your dissemination efforts for this output. Describe this for publications if you have made any effort beyond those of the sponsor of the publication (journal, book, proceedings, etc.). Please include important aspects of dissemination such as:

- Stage and scope (e.g., local, regional, national) of dissemination
- Dissemination activities
- Identification and tailoring of materials for reaching different audience/user types
- Collaboration with audience/users in identifying content and medium needs/preferences
- Delivery of information through multiple media types and sources for optimal reach and accessibility
- Evaluation of your dissemination efforts and impacts

Part C. Grant-level Questions

Please respond to these final questions for your overall grant, not by each output specifically as in Section B.

C1. In the space below please describe what types of planning, project management, and budgetary processes were used to promote high quality outputs. In your statement consider the following types of questions:

- Which processes were useful and how? How could they be improved?
- Did you dedicate funds for quality assurance activities?
- How did you track progress and spending against your original plans for the grant?
- If grants or projects were jointly funded by NIDRR and other extramural or intramural sources, how did you ensure that NIDRR resources were used exclusively for NIDRR-funded activities?

C2. Have the results of the research and development outputs from this grant, or prior NIDRR grants, been used to inform the development of new grant applications or other kinds of projects?

No _____
Yes _____

If yes, please use the space below to briefly describe what new grant applications, other projects, funding opportunities, or collaborations have emerged.

C3. Please share any perspectives you may have about how NIDRR's key processes (e.g., priority setting, peer review, and/or grants management) influence results, such as successful grants and high quality outputs.

**App-B-2d External Evaluation of the National Institute on Disability and Rehabilitation
Research (NIDRR) and its Grantees**

**Committee Member Review Procedures for Summative Evaluation
(Revised 11-08-10)**

A. Review Subgroups: Each subgroup that will be reviewing outputs will be composed of five Committee members. For each output one committee member will be assigned as the primary reviewer; the remaining four committee members will be secondary reviewers.

B. Output Rating Procedures:

1. All reviewers will independently rate outputs using the following quality criteria (Dimensions of these criteria are shown on the attached rating sheet.):

- Technical quality of output
- Advancement of knowledge or the field (research, practice, or policy)
- Likely impact
- Dissemination

The following scale will be used for rating the outputs:

Poor Quality				Good Quality				Excellent Quality
1	2	3	4	5	6	7		

2. The rating will be based on review of hard copy and electronic materials (i.e., articles/descriptive information about output and questionnaire responses) prior to the subcommittee meeting.

3. The grantee's final summary APR, and a list of all outputs reported over the course of the project, is provided for contextual purposes. The APR also will be used to inform an overall, qualitative grant-level assessment.

4. Multiple outputs of one grant will generally be rated independently of each other. However, in some cases outputs may be rated as a pair with one score applied. This could occur when one output is a derivative or different expression of another output, and when the PI responses to criterion questions are basically the same. Examples of these include:

- A manual describing a device (1) and a patent of the device (2)

- A publication describing how a new technology for assessing a condition can be applied in disability rehabilitation (1) and a description of the technology itself (2)
- A software application (e.g., map reader for persons with visual impairments) (1) and web-based method for individualizing the software for users (2)

5. The meeting will be structured as follows.

- The primary reviewer will open discussion of each output by presenting a brief summary of the output and then his/her rationale for rating each relevant criterion (up to four) plus the overall score,
- Secondary reviewers will then present their ratings for each output and a brief rationale.
- Using the same criteria, the subgroup will then develop consensus group ratings for each output. Discussion will be facilitated by the subgroup chair. If there is a subgroup member with a significantly divergent view, his/her score and rationale will be captured separately.
- Staff will document discussion points that lead to the consensus group ratings and will record the subgroup's rationale for each criterion, the overall rating, and the grant performance rating in a brief narrative.
- At the end of the review of each output, the individual subgroup members' rating sheets will be gathered.

C. Grant Assessment

Once all outputs of an individual grant are reviewed, the subgroup will consider and rate the grant's overall performance. The outputs reviewed had been identified by the grant's Principal Investigator as the "top" two outputs per project, which best reflected the grant's achievements. Taking into consideration this designation, the consensus group ratings of the entire set of outputs, and the grant's overall purpose and objectives (using the grant's APR), the subgroup will assign a grant performance rating using the same 7-point scale. These grant-level ratings and their rationale will also be documented by staff.

Committee Member: _____
Output ID: _____

Appendix B

App-B-2e Committee Member Rating Sheet of the Quality of Outputs

Grantee ID: _____

Date of Review: _____

Output to be Reviewed: _____

<i>To be completed by NRC staff</i>				
Output Title: _____				
Research Output: _____ Development Output: _____				
Type and Subtype of Output (marked below):				
Type of Publication	Type of Tool, Measure, or Intervention Protocol	Type of Technology Product or Device	Type of Informational Product	
1. abstract	1. checklist	1. industry standards/guidelines	1. training manuals/curricula	
2. book	2. survey or interview schedule	2. software or netware	2. fact sheets	
3. book chapter	3. diagnostic or assessment instrument	3. invention	3. newsletters	
4. journal article	4. outcome measure	4. patent, license, or disclosures	4. audiovisual materials	
5. proceedings	5. intervention protocol or program	5. working prototype	5. marketing tools	
6. technical	6. statistical technique	6. product evaluated or field tested	6. educational aids	
7. web journal	7. database	7. product transferred to industry for potential commercialization	7. websites or other internet sites	
8. other	8. other	8. product in marketplace	8. other	

Committee Member: _____
 Output ID: _____

Appendix B

Quality Criteria and Dimensions

For each criterion provide one rating using the scale below:

Poor				Good			Excellent
1	2	3	4	5	6	7	

Criteria and Dimensions	Score
Technical Quality of Output • Applying standards of science and technology • Appropriate methodology (quantitative or qualitative design and statistics) • Accessibility, usability, etc. Score Rationale:	
Advancement of Knowledge or the Field (research, practice, or policy as relevant) • Science: Establishment of methods, tools, theory • New information • Closing an identified gap • New technology • Innovative or novel Score Rationale:	
Likely or Demonstrated Impact On: • Science (impact factor, citations) • Consumers (people with disabilities: health, quality of life, participation) • Provider practice • Health and social system • Social and health policy • Private sector/commercialization • Other Score Rationale:	
Dissemination • Identification and tailoring of materials for reaching different audience/user types • Collaboration with audience/users in identifying content and medium needs/preferences • Delivery of information through multiple media types and sources for optimal reach and accessibility • Evaluation of dissemination efforts and impacts • Commercialization/patenting of devices, if applicable Score Rationale:	
Overall Score Score Rationale:	

Appendix C

Acronyms

Appendix C

Acronyms

AAC: Augmentative and Alternative Communication. AAC refers to any method of communicating without speech such as using signs, gestures, and electronic and non-electronic devices.

ADA: Americans with Disability Act. The ADA gives civil rights protections to individuals with disabilities and guarantees equal opportunity for individuals with disabilities in public accommodations, employment, transportation, State and local government services, and telecommunications.

ADL: Activities of daily living. ADLs include activities such as eating, dressing, grooming, or shaving. Nurses, occupational and physical therapists are the main coaches for ADL, which is sometimes called DLS or daily living skills.

APAER: Annual Portfolio Assessment Expert Review. The APAER process was developed by NIDRR to assess its progress in meeting Federal performance requirements under GPRA and PART and to capture progress of its grantees using a three-year cycle, with one-third of NIDRR's portfolio reviewed every three years by expert panels. The

1 APAER system is being replaced by an updated approach to evaluating NIDRR and its
2 grants.

3

4 APR: Annual Performance Report. The APR is completed annually by NIDRR grantees
5 to report on project activities and outcomes including publications, Measures and
6 Intervention Products, Technology Products and Devices and informational products.

7

8 ARRT: Advanced Rehabilitation Research Training. The ARRT program provides
9 rehabilitation research training for persons with clinical or other experience, who may be
10 lacking certain formal research training. Grants are made to institutions to recruit
11 qualified persons with doctoral or similar advanced degrees with clinical, management,
12 basic science, or engineering research experience and prepare them to conduct
13 independent research on problems related to disability and rehabilitation.

14

15 AT: Assistive Technology: The utilization of technology, strategies, and methods in
16 enabling individuals to master tasks at home, school, work, increase independence, and
17 quality of life—use of computers, toys, controls, equipment, communications,
18 modifications, etc. Usually done by OT or PT.

19

20 BMS: Burn Model Systems Centers. The NIDRR-funded BMS develops exemplary
21 burn care and advances the research base of rehabilitation services for burn survivors

22

23 CAM: - Contracts and Acquisitions Management.

1

2 CCR: Central Contractor Registration. CCR is the primary contractor registrant database
3 for the U.S. Federal Government. CCR collects, validates, stores and disseminates data in
4 support of agency acquisition missions.

5

6 CFDA: Catalog of Federal Domestic Assistance. A catalog that lists, by assigned
7 numbers (CFDA numbers) of all federal programs available to state and local
8 governments; federally-recognized Indian tribal governments; territories of the United
9 States; domestic public, quasi-public, and private profit and non-profit organizations and
10 institutions; specialized groups; and individuals.

11

12 CFR: Code of Federal Regulations. The CFR is the codification of the general and
13 permanent rules and regulations (sometimes called administrative law) published in the
14 *Federal Register* by the executive departments and agencies of the Federal Government
15 of the United States.

16

17 CIL: Center for Independent Living. Not-for-profit, charitable, organizations that
18 advocate for the civil rights and service needs of people with disabilities so that they can
19 live independently in the community.

20

21 CIRRIE: Center for International Rehabilitation Research Information and Exchange (A
22 NIDRR-funded grant that promotes international exchange of rehabilitation research
23 information

1

2 CORC: Coordination, Outreach and Research Center. The CORC is a NIDRR-funded
3 center that coordinates many aspects of the NIDRR-funded DBTACs.

4

5 DBTAC: Disability and Business Technical Assistance Center (NIDRR-funded projects
6 that provide technical assistance, information and training to state and local governments
7 and private businesses regarding the Americans with Disabilities Act (ADA) and
8 facilitate compliance with the ADA)

9

10 DCoE: Defense Centers of Excellence on Psychological Health and Traumatic Brain
11 Injury of the U.S. Department of Defense.

12

13 DOD: Department of Defense.

14

15 DOL: Department of Labor.

16

17 DRRP: Disability and Rehabilitation Research Projects. NIDRR-funded DRRPs are
18 projects with special emphasis on research, demonstrations, training, dissemination,
19 utilization, and technical assistance. Projects may include combinations of these
20 activities, and are usually funded for one cycle only of three to five years.

21

22 DRS: 1. Division of Research Sciences. One of the two major divisions in NIDRR. 2.
23 Division of Regulatory Services. A division within ED's Office of the General Council

1 that deals with developing and interpreting regulations, including development of Federal
2 register documents such as notices of proposed and final priorities and notices inviting
3 applications..
4

5 DVBIC: Defense and Veterans Brain Injury Center. A DOD and VA system that serves
6 active duty military, their dependents and veterans with traumatic brain injury (TBI)
7 through state-of-the-art medical care, innovative clinical research initiatives and
8 educational programs.
9

10 EBP: Evidence-Based Practice. EBP refers to preferential use of health, education and
11 rehabilitative interventions for which systematic empirical research has provided
12 evidence of statistically significant effectiveness as treatments for specific problems.
13

14 EDCAPS: Education Central Automated Processing System. EDCAPS is an integrated
15 financial management and information system to support the Department's core financial
16 and management information functions.
17

18 EDGAR: Education Department General Administrative Regulations. EDGAR is a
19 compilation of administrative regulations that relate to the Department of Education.
20

21 ES: Executive Secretary (Usually refers to the Education Departments office of the
22 Executive Secretary)
23

1 FIP: Field Initiated Projects. The FIP program is a NIDRR-funded program of
2 investigator-initiated research.

3
4 FR: Federal Register. The Federal Register is the official daily publication for rules,
5 proposed rules, and notices of Federal agencies and organizations, as well as executive
6 orders and other presidential documents.

7
8 G5: The system that will replace the current GAPS (see below).

9
10 GAN: Grant Award Notification. The document that officially acknowledges and
11 implements all grantee grant actions, such as award of grant, continuation awards,
12 changes in project directors, time extensions, etc.

13
14 GAPS: Grant Administration and Payment System. GAPS is ED's grant administration
15 and payment system. It supports planning, pre-award, award management and post-award
16 stages of the Department grant programs and interfaces with various program office
17 feeder systems to support the planning, scheduling and award processes of these
18 programs. In addition, GAPS processes the payments for all Department grant programs.

19
20 GPO: Government Printing Office.

21

1 GCST: Grants and Contracts Services Team (within OSERS). The GCST supports the
2 grants function within OSERS through maintaining the official grant files, coordinating
3 the peer review contract, assembling application packages, and other functions.
4

5 GPOS: Grants Policy and Oversight Staff
6

7 GPRA: Government Performance and Results Act. Under GPRA, federal agencies are
8 required to develop long-term Strategic Plans defining general goals and objectives for
9 their programs, to develop Annual Performance Plans specifying measurable
10 performance goals for all of the program activities in their budgets, and to publish an
11 Annual Performance Report showing actual results compared to each annual performance
12 goal.
13

14 HHS: Department of Health and Human Services

15 ICC: Interagency Coordinating Council on Emergency Preparedness and Individuals
16 with Disabilities. The ICC was established to ensure that the federal government
17 appropriately supports safety and security for individuals with disabilities in disaster
18 situations.

19 ICDR: Interagency Committee on Disability Research. An interagency committee,
20 coordinated by NIDRR, that promotes coordination, collaboration, and cooperation
21 among federal departments and agencies conducting disability and rehabilitation
22 research.

1

2 ICF: International Classification of Function, Disability and Health. The ICF is a
3 classification of health and health-related domains. These domains are classified from
4 body, individual and societal perspectives by means of two lists: a list of body functions
5 and structure, and a list of domains of activity and participation. Since an individual's
6 functioning and disability occurs in a context, the ICF also includes a list of
7 environmental factors.

8

9 IES: Institute for Educational Services. The IES is housed within ED's Office or
10 Educational Research and Improvement. The mission of IES is to provide rigorous
11 evidence on which to ground education practice and policy. This is accomplished through
12 the work of its four centers.

13

14 ILC: Independent Living Center. Not-for-profit, charitable, organizations that advocate
15 for the civil rights and service needs of people with disabilities so that they can live
16 independently in the community.

17

18 IOM: Institute of Medicine

19

20 ISE: Interagency Subcommittee on Employment – One of the subcommittees of the
21 ICDR.

22

1 KT: Knowledge Translation. KT involves the process of ensuring new research
2 knowledge ultimately improves the lives of people with disabilities. It involves not only
3 knowledge validation and dissemination, but also the transfer of technology from
4 research and development to the commercial marketplace.

5
6 LRP: Long Range Plan. This usually refers to NIDRR's long range plan.

7
8 MS: Model Systems (MS) Centers. These centers establish innovative projects for the
9 delivery, demonstration, and evaluation of comprehensive medical, vocational, and other
10 rehabilitation services to meet the wide range of needs of individuals with spinal cord
11 injuries, traumatic brain injury, and burns. Average grant length is 5 years.

12
13 MSKTC: Model Systems Knowledge Translation Center. This NIDRR-funded grant
14 facilitates the dissemination of research to practice and consumer education of the
15 NIDRR-funded TBI, SCI and Burn model systems projects.

16
17 NARIC: National Rehabilitation Information Center. A NIDRR-funded clearinghouse
18 for a broad range of disability and rehabilitation information from a variety of sources
19 such as NIDRR-funded projects, other federal programs, journals, periodicals,
20 newsletters, films, and videotapes.

21
22 NARRTC: National Association of Rehabilitation Research and Training Centers.

23

1 NCC: Non-competing Continuation.

2

3 NCDDR: National Center for the Dissemination of Disability Research. A NIDRR-
4 funded center for increasing the effective use of NIDRR-sponsored research results in
5 shaping new technologies, improving service delivery, and expanding decision-making
6 options for people with disabilities and their families.

7

8 NCE: No Cost Extension

9

10 NFP: Notice of Final Priority. A Federal Register document that announces an agency's
11 priorities and requirements for a grant competition

12

13 NIA: Notice Inviting Applications. A Federal register document that announces the
14 opening of an agency's grant competition, specifying submission requirements,
15 deadlines, etc.

16

17 NIH: National Institutes of Health.

18

19 NINDS: National Institute of Neurological Disorders and Stroke of the National
20 Institutes of Health.

21

22 NIDRR: National Institute on Disability and Rehabilitation Research.

23

1 NPP: Notice of Proposed Priority. A Federal Register document that announces an
2 agency's priorities and requirements for a grant competition in proposed format. The
3 NPP requests public comment on the proposed priorities. Comments are reviewed and
4 the priority may be re-written base upon those comments.

5

6 NRC: National Research Council

7

8 OAS: Office of the Assistant Secretary (this usually refers to the OAS within OSERS)

9

10 ODEP: Office of Disability Employment Policy (within the Department of Labor)

11

12 OGC: Office of General Council. This ED office provides legal guidance to the
13 department and reviews documents such as NFP and NIAs to ensure they are legally
14 correct.

15

16 OMB: Office of Management and Budget.

17

18 OS: Office of the Secretary (usually refers to the OS within ED)

19

20 OSEP: Office of Special Education Programs. OSEP is one of the three program units
21 within OSERS. OSEP is dedicated to improving results for infants, toddlers, children
22 and youth with disabilities ages birth through 21 by providing leadership and financial
23 support to assist states and local districts.

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OSERS: Office of Special Education and Rehabilitative Services

PART: Program Assessment Rating Tool. The PART is a diagnostic tool used to assess the performance of Federal programs and to drive improvements in program performance. PART reviews help inform budget decisions and identify actions to improve results. Agencies are held accountable for implementing PART follow-up actions, also known as improvement plans, for each of their programs.

PB&E: Program, Budget and Evaluation. One of the two major divisions in NIDRR.

RCT: Randomized Controlled Trials. An RTC is a type of scientific experiment most commonly used in testing the efficacy or effectiveness of healthcare services (such as medicine or nursing) or health technologies (such as pharmaceuticals, medical devices or surgery). RCTs involve the random allocation of different interventions (treatments or conditions) to subjects. As long as numbers of subjects are sufficient, this ensures that both known and unknown confounding factors are evenly distributed between treatment groups.

RERC: Rehabilitation Engineering Research Center. NIDRR-funded RERCs conduct programs of advanced research of an engineering or technical nature designed to apply advanced technology, scientific achievement, and psychological and social knowledge to solve rehabilitation problems and remove environmental barriers.

1

2 RESNA: Rehabilitation Engineering and Assistive Technology Society of North
3 America.

4

5 RRTC: Rehabilitation Research and Training Center. NIDRR-funded RRTCs conduct
6 coordinated and integrated advanced programs of research targeted toward the production
7 of new knowledge, which may improve rehabilitation methodology and service delivery
8 systems, alleviate or stabilize disabling conditions, or promote maximum social and
9 economic independence for persons with disabilities.

10

11 RSA: Rehabilitation Services Administration. RSA is one of the three program units
12 within OSERS. RSA oversees grant programs that help individuals with physical or
13 mental disabilities to obtain employment and live more independently through the
14 provision of such supports as counseling, medical and psychological services, job
15 training and other individualized services.

16

17 RSD: Research Sciences Division within NIDRR (Same as DRS). One of the two major
18 divisions in NIDRR.

19

20 SAMHSA: Substance Abuse and Mental Health Administration (located within the
21 Department of Health and Human Services).

22

1 SBIR: Small Business Innovation Research. SBIR programs stimulate technological
2 innovations in the private sector, strengthen the role of small business in meeting Federal
3 research or research and development (R&D) needs, increase the commercial application
4 of research supported by the Department, and improve the return on investment from
5 federally funded research for economic and social benefits for the Nation. All SBIR
6 projects funded by NIDRR must address the needs of individuals with disabilities and
7 their families.

8
9 SEDL: Southwest Educational Development Laboratory (The NIDRR grantee that
10 conducts the National Center for the Dissemination of Disability Research)

11
12 SCI: Spinal Cord Injury. Impairment or loss of motor and sensory function in the
13 cervical, thoracic, lumbar, or sacral neurologic segments secondary to damage of neural
14 elements within the spinal canal.

15
16 SCIMS: Spinal Cord Injury Model Systems Centers. The SCIMS program studies the
17 course of recovery and outcomes following the delivery of a coordinated system of care
18 for individuals with SCI. Under this program, SCIMS centers provide comprehensive
19 rehabilitation services to individuals with SCI and conduct spinal cord research, including
20 clinical research.

21
22 SSDI: Social Security Disability Income. SSDI is a long-term disability income program
23 sponsored by the Social Security Administration that provides benefits to disabled

1 workers who are under age 65 and who have paid a specified amount of Social Security
2 tax for a prescribed number of quarter-year periods.

3
4 SSI: Supplemental Security Income. A public assistance program for the aged, blind, and
5 disabled that is administered by the Social Security Administration (SSA).

6
7 TANF : Temporary Assistance for Needy Families. TANF was formerly known as
8 "welfare." It provides cash assistance to indigent American families with dependent
9 children through the United States Department of Health and Human Services.

10
11 TBI: Traumatic Brain Injury. An insult to the brain caused by an external physical force
12 that may produce a diminished or altered state of consciousness that results in an
13 impairment of cognitive abilities or physical functioning and/or a disturbance of
14 behavioral or emotional functioning.

15
16 TBIMS: Traumatic Brain Injury Model Systems Centers. The aim of the program is to
17 demonstrate the benefits of a coordinated system of neurotrauma and rehabilitation care
18 and to conduct innovative research on all aspects of care for those who sustain traumatic
19 brain injuries.

20
21 TT: Technology transfer. TT is the process of sharing of skills, knowledge,
22 technologies, methods of manufacturing, samples of manufacturing and facilities among
23 industries, universities, governments and other institutions to ensure that scientific and

1 technological developments are accessible to a wider range of users who can then further
2 develop and exploit the technology into new products, processes, applications, materials
3 or services.

4

5 VA: (Department of) Veterans Affairs.

6

7 VR: Vocational Rehabilitation.

8

Appendix D

Committee and Staff Biographical Sketches

Appendix D

Biographical Sketches of Committee Members and Staff

David H. Wegman, Chair, is Professor Emeritus in the School of Health and Environment at the University of Massachusetts, Lowell. Dr. Wegman was appointed professor and founding chair of the Department of Work Environment in 1987. He served a five-year term as Dean of the School of Health and Environment (2003-2008) after which he returned to the faculty until his retirement at the end of 2009. He continues to serve as adjunct professor at the Harvard School of Public Health. He received his B.A. from Swarthmore College, and his M.D. and M.Sc. from Harvard University and is Board Certified in Preventive Medicine (Occupational Medicine). Previously he served as Director of the Division of Occupational and Environmental Health at the UCLA School of Public Health and on the faculty at Harvard School of Public Health. Dr. Wegman has focused his research on epidemiologic studies of occupational respiratory disease, musculoskeletal disorders, and cancer and has published over 200 articles in the scientific literature. He has also written on public health and policy issues concerning hazard and health surveillance, methods of exposure assessment for epidemiologic studies, the development of alternatives to regulation and the use of participatory methods to study occupational health risks. He has served as chair of the NRC-IOM Committees on Health and Safety Needs of Older Workers and the Health and Safety Consequences of Child Labor, as well as the Committee to Review the NIOSH Research Programs. He has also been a member of the NRC-IOM Panel on Musculoskeletal Disorders and Work, the IOM Committees to Review the Health Consequences of Service During the Persian Gulf War and to Review Gender Differences in Susceptibility to Environmental Factors. He is currently chair of the NRC Committee on The Role of Human Factors in Home Health Care.

Thomas J. Armstrong is a professor in the Departments of Industrial and Operations Engineering and Biomedical Engineering at The University of Michigan. He is also Director of the University of Michigan Center for Ergonomics and was Director of the Rehabilitation Engineering Research Center on Ergonomics. Dr. Armstrong has a B.S.E. in aerospace engineering, an M.P.H. in industrial health, and a Ph.D. in industrial health, physiology, and engineering all from the University of Michigan. Dr. Armstrong's research is concerned with performance and health issues in manual work. His research includes: development of methods for analyzing physical work requirements, development of biomechanical models of hand function, analysis of the relationship between physical work requirements and musculoskeletal disorders, design of work stations, hand tools and keyboards, identifying ways of facilitating the

1 return to work of injured workers, analysis and design of jobs for accommodation of restricted
2 workers and design of ergonomic programs for control of work related musculoskeletal
3 disorders. He has conducted research and training within the automobile, aerospace, electronics,
4 computer, office, and food processing industries. His research has resulted in numerous articles,
5 chapters and reports on upper limb biomechanics, carpal tunnel syndrome, tendinitis, job
6 analysis, vibration, tools, workstations and computer-aided design. Dr. Armstrong is on the
7 editorial boards for *Human Factors and Ergonomics*, the *Journal of Occupational Rehabilitation*
8 and the *Scandinavian Journal of Work Environment and Health*. He is a Fellow in the American
9 Industrial Hygiene Association, the American Institute for Medical and Biological Engineering,
10 the Human Factors and Ergonomics Society, and the International Ergonomics Association. Dr.
11 Armstrong served on the NRC committee that organized the Workshop to Evaluate Work-
12 Related Musculoskeletal Injuries: The Research Base.

13
14 **Burt S. Barnow** is the Amsterdam Professor of Public Service and of Economics at the George
15 Washington University. Dr. Barnow received a B.S. in economics from MIT and a Ph.D. in
16 economics from the University of Wisconsin at Madison. Prior to joining Johns Hopkins, he was
17 vice president of a consulting firm in Washington, D.C. He served nine years in the U.S.
18 Department of Labor, most recently as director of the Office of Research and Evaluation for the
19 Employment and Training Administration. As a labor economist, much of Dr. Barnow's work
20 focuses on labor markets; over the years he has conducted a number of studies looking at
21 whether particular labor markets experience shortages of workers and, if so, why the shortages
22 have arisen. Dr. Barnow has also conducted many studies of occupational training programs,
23 including studies of how they are being implemented and how effective they have been. Dr.
24 Barnow teaches the core course on program evaluation in the public policy program, and he has
25 conducted evaluations on a variety of social programs including training programs, welfare, child
26 support, and fatherhood programs. His current research includes an evaluation of the impact of
27 the Department of Labor's High Growth Job Training Initiative, the development and evaluation
28 of pilot programs to test self-sufficiency strategies for welfare recipients for the U.S. Department
29 of Health and Human Services, a study of the implementation of the Recovery Act for workforce
30 investment programs for the U.S. Department of Labor, and an analysis of whether veterans are
31 receiving priority of service at One-Stop Career Centers for the U.S. Department of Labor. He
32 has been a member of seven NRC Committees, most recently committees on Approaches for an
33 Evaluation of the NIST/NRC Postdoctoral Research Associateships Program, a Review of
34 United States Institute of Peace Senior Fellows Program, and a Review of the Title VI and
35 Fulbright Hays International Education Programs, and the Committee to Review NASA's
36 Workforce, and the NRC Committee to Review EPA's Title 42 Hiring Authority for Highly
37 Qualified Scientists and Engineers. He also served two terms on the NRC Board on Higher
38 Education and the Workforce.

39
40 **Leighton Chan** is Chief of the Rehabilitation Medicine Department at the Clinical Center of the
41 National Institutes of Health. He has an M.P.H from the University of Washington and an M.D.
42 from the University of California, Los Angeles. Dr. Chan completed postgraduate training in
43 Physical Medicine and Rehabilitation at the University of Washington. Subsequently, he
44 completed a Robert Wood Johnson Clinical Scholar Fellowship and was a Congressional Fellow
45 for the Honorable Jim McDermott (Washington). From 1994 to 2006, Dr. Chan was on the
46 faculty of the University of Washington's Department of Rehabilitation Medicine. From 2002 to

1 2006, he was associate professor. He is board certified in physical medicine and rehabilitation
2 and in electrodiagnostic medicine. Dr. Chan's research interests include health services research,
3 quality of care given to Medicare beneficiaries, and Medicare payment policy issues. He has
4 published more than 60 peer reviewed articles and numerous book chapters. Dr. Chan's awards
5 include the Young Academician Award from the Association of Academic Physiatrists, two
6 outstanding teacher awards from the University of Washington School of Medicine, and a
7 Presidential Citation Award for excellence in research by the American Academy of Physical
8 Medicine and Rehabilitation. Dr. Chan is a member of the Institute of Medicine and is a current
9 IOM Membership Section Leader.

10
11 **Peter C. Esselman** is professor and chair of the Department of Rehabilitation Medicine at the
12 University of Washington, as well as Chief of rehabilitation medicine at Harborview Medical
13 Center in Seattle. He has an M.D. from the University of Washington School of Medicine. His
14 clinical interests include the rehabilitation of individuals after traumatic injuries with a focus on
15 traumatic brain injury and burn injuries. He is also interested in quality improvement. Dr.
16 Esselman was an Intern in the Department of Medicine, and a Resident as well as Chief Resident
17 in the Department of Rehabilitation Medicine at the University of Washington. Dr. Esselman
18 has published over 50 journal articles, and 5 book chapters. He is on the editorial board of the
19 American Journal of Physical Medicine & Rehabilitation. He is a member of the Health Policy
20 Legislation Committee of the American Academy of Physical Medicine and Rehabilitation and
21 was Chair of the Association of Academic Physiatrists Task Force on Chronic Disease and
22 Disability Education. He is a member of the American Academy of Physical Medicine and
23 Rehabilitation, the American Burn Association, and the Association of Academic Physiatrists.
24 In 2001 he won the Harborview Medical Center Service Excellence Award. He was a member
25 of the IOM Committee on Traumatic Brain Injury.

26
27 **Walter R. Frontera** is Professor of Physical Medicine and Rehabilitation (PM&R) and
28 Physiology at the University of Puerto Rico (UPR). Dr. Frontera completed his M.D. and
29 residency in PM&R in 1983 at the University of Puerto Rico and his Ph.D. in applied anatomy
30 and physiology at Boston University in 1986. In 1995 he spent a sabbatical year at the
31 Karolinska Hospital in Stockholm, Sweden in the Department of Clinical Neurophysiology
32 studying the effects of aging on the biochemical and contractile properties of single human
33 muscle fibers. In 1996 he was recruited to Harvard Medical School to establish the Department
34 of PM&R and was appointed the Earle P. and Ida S. Charlton Professor and Chairman of the
35 Department of PM&R at Harvard Medical School and Spaulding Rehabilitation Hospital. He
36 was also the Chief of Service at the Massachusetts General Hospital and the Brigham and
37 Women's Hospital. His main research interest is the study of the mechanisms underlying muscle
38 atrophy and weakness in elderly and the development of rehabilitative interventions for
39 sarcopenia. Dr. Frontera has more than 200 scientific publications including more than 75 peer-
40 reviewed articles and 10 edited books. Currently, Dr. Frontera serves as the Editor-in-Chief of
41 *The American Journal of PM&R*, Regional Vice-President of the International Society for
42 PM&R, and President of the International Federation of Sports Medicine. He has received
43 several awards including Best Scientific Research Paper (3 times) presented by the American
44 Academy of PM&R, the Distinguished Academician Award in 2005 presented by the
45 Association of Academic Physiatrists, and the Harvard Foundation Award for his contributions

1 to the field of PM&R. In 2008 he was elected to the Institute of Medicine. He currently serves
2 on the IOM Committee of Medical Experts to Assist Social Security on Disability Issues.

3
4 **Glenn Fujiura** is an Associate Professor of Human Development, Associate Dean for Academic
5 Affairs and Director of Graduate Studies for the Department of Disability and Human
6 Development in the College of Applied Health Sciences at the University of Illinois at Chicago.
7 Dr. Fujiura's research has focused on the fiscal structure and demography of the disability service
8 system, on family policy, evaluation of long-term care services, poverty and disability, ethnic
9 and racial issues in disability, and on the statistical surveillance of disability. In addition, he has
10 a long-standing interest in research methodology, statistical analysis, and philosophy of science.
11 He teaches research methods, advanced research concepts, and statistics for the graduate
12 program. Current major projects include analyses of family demographics, evaluation of state
13 disability spending, cognitive testing of health surveys for persons with intellectual disabilities,
14 evaluation of international disability statistical surveillance, health statistics and intellectual
15 disability, and the application of knowledge utilization models on ADA technical assistance. He
16 has worked extensively in both the creation of large national data sets in intellectual and
17 developmental disabilities, and in the secondary analysis of national statistical surveillance
18 systems. Past service includes Chair of the U.S. Administration on Developmental Disabilities
19 Commissioner's Multicultural Advisory Committee, was a 1999 recipient of the National
20 Rehabilitation Association's Switzer Scholar award, a member of the President's Committee on
21 Mental Retardation during the Clinton administration, Cultural Diversity Advisory Committee
22 for the National Council on Disability, and NIDRR's Long Range Plan Steering Committee.

23
24 **Bruce M. Gans** is Executive Vice President and Chief Medical Officer for the Kessler Institute
25 for Rehabilitation, based in West Orange, New Jersey. He is also the National Medical Director
26 for Rehabilitation for Select Medical Corporation, the parent company for Kessler. In addition,
27 Dr. Gans holds an appointment as Professor of Physical Medicine and Rehabilitation at the
28 UMDNJ-New Jersey Medical School. Dr. Gans also is on the Board of Directors of the Allied
29 Health Research Institute, which is a non-profit organization focused on improving rehabilitation
30 therapy access. Dr. Gans received his M.D. degree from the University of Pennsylvania School
31 of Medicine in Philadelphia and an MS in Biomedical Electronic Engineering from the Moore
32 School of Engineering at the University of Pennsylvania. He also holds an MS degree from the
33 University of Washington. He served his medical internship at the Philadelphia General Hospital
34 and residency in Physical Medicine & Rehabilitation at the University of Washington, Seattle.

35 Dr. Gans received his BS degree in electrical engineering from Union College, Schenectady,
36 New York. Dr. Gans has published extensively, and has held more than \$10M in research and
37 educational grants from the public and private sectors. He is editor of the major textbook,
38 Physical Medicine & Rehabilitation: Principles and Practice, Fourth Edition, 2004. He also
39 serves as an Associate Editor of the American Journal of Physical Medicine and Rehabilitation.

40 His research has focused on pediatric trauma rehabilitation, quantitative assessment of motor
41 performance, rehabilitation engineering, rehabilitation health services delivery, and primary care
42 for the disabled. Dr. Gans has been honored with recognition in "The Best Doctors in America,"
43 and has received the AHA's prestigious Brent England Award for Excellence in Rehabilitation
44 Management (1995), and the AMRPA's INDE Service Award (2005). The Association of
45 Academic Physiatrists awarded him their Outstanding Service Award in 2000. In 2001, he was
46 selected to deliver the 34th Annual Walter J. Zeiter Lecture to the American Academy of

1 Physical Medicine and Rehabilitation. In 2008 he was the recipient of the Distinguished
2 Member Award from the AAPM&R.

3
4 **Ian Graham** is Vice-President of the Knowledge Translation Portfolio at Canadian Institutes of
5 Health Research. At CIHR, he is responsible for knowledge translation, partnerships and citizen
6 engagement, communication and public outreach, and evaluation and analysis. Dr Graham is on
7 leave from his position as Associate Professor in the School of Nursing, University of Ottawa
8 and Senior Social Scientist in the Clinical Epidemiology Program of the Ottawa Hospital
9 Research Institute. He holds cross-appointments in the Departments of Medicine and
10 Epidemiology & Community Medicine and is an adjunct associate professor in the School of
11 Nursing at Queen's University, Kingston, Ontario. Dr. Graham obtained a B.A. in sociology
12 from McGill University, an M.A. in sociology from the University of Victoria, and a Ph.D. in
13 medical sociology from McGill University. Dr. Graham's research has largely focused on
14 knowledge translation (the process of research use) and conducting applied research on strategies
15 to increase implementation of research findings and evidence-based practice. He has also
16 advanced KT science through the developed two planned action models, the Ottawa Model of
17 Research Use and more recently the Knowledge to Action Model. Specific research projects
18 have related to the adaptation, implementation, and quality appraisal of clinical practice
19 guidelines, as well as the uptake of guidelines and decision support tools by practitioners. He is
20 co-editor of Knowledge Translation in Health Care published by Wiley-Blackwell (2009).

21
22 **Lisa I. Iezzoni** is professor of medicine at Harvard Medical School and Director of the Mongan
23 Institute for Health Policy at Massachusetts General Hospital. She has an M.D. from Harvard
24 Medical School. Dr. Iezzoni has spent more than two decades conducting health services
25 research focusing on three primary areas: risk adjustment methods for predicting cost and
26 clinical outcomes of care; use of administrative data for assessing health care quality; and health
27 care experiences and outcomes of persons with disabilities. Dr. Iezzoni has personal experience
28 in the later area (she has had multiple sclerosis since age 22). After spending 16 years as Co-
29 Director of Research in the Division of General Medicine and Primary Care at Boston's Beth
30 Israel Deaconess Medical Center, Dr. Iezzoni joined the IHP as Associate Director in 2006. Dr.
31 Iezzoni has led numerous research grants with funding from the Agency for Healthcare Research
32 and Quality, National Institutes of Health, the Health Care Financing Administration, The Robert
33 Wood Johnson Foundation, and other private foundations. An internationally recognized expert
34 in risk adjustment, she has edited *Risk Adjustment for Measuring Health Care Outcomes*, now in
35 its third edition. Dr. Iezzoni began her disability research with a 1996 Investigator Award in
36 Health Policy Research from RWJF, and the book summarizing this work, *When Walking Fails:
37 Mobility Impairments of Adults with Chronic Conditions*, appeared in 2003. A book considering
38 disability experiences more broadly, *More Than Ramps: A Guide to Improving Health Care
39 Quality and Access for People with Disabilities* was published in 2006. Another book, *Multiple
40 Sclerosis*, will appear in early 2010. Dr. Iezzoni has also published numerous original articles,
41 editorials, and commentaries in major medical and health services research journals. She has
42 been a member of many IOM committees including, the IOM Committee on Identifying Priority
43 Areas for Quality Improvement, to Evaluate Measures of Health Benefits for Environmental,
44 Health, and Safety Regulation, and Disability in America: A New Look. Dr. Iezzoni is a
45 member of the Institute of Medicine.

1 **Alan M. Jette** currently directs the Health & Disability Research Institute at the Boston
2 University School of Public Health where he also serves as Professor of Health Policy &
3 Management. He received his M.P.H. and Ph.D. in public health from the University of
4 Michigan. Dr. Jette's research interests include late-life exercise, evaluation of treatment
5 outcomes, and the measurement, epidemiology, and prevention of disability. He has published
6 over 125 articles on these topics in the rehabilitation, geriatrics, and public health literature. Dr.
7 Jette is Research Director for the New England Regional Spinal Cord Injury Center based at
8 Boston University Medical Center and serves as Director of the Boston University Post Doctoral
9 Research Fellowship in Rehabilitation Outcomes and Effectiveness Research. He serves on the
10 Executive Committee of the Boston Claude Pepper Older Americans Independence Center. His
11 current work focuses on the development and dissemination of contemporary outcome
12 measurement instruments to evaluate the quality of health care. Dr. Jette was a member of the
13 NRC-IOM Committee to Review the Social Security Administration's Disability Decision
14 Process Research, was Chair of the IOM Committee on The Future of Disability in America, and
15 was Chair of the NRC Steering Committee to Design and Conduct a Public Workshop on New
16 Survey Measures of Cognitive and Functional Disability: Going Beyond ADLs and IADLs.

17
18 **Thubi Kolobe** is a professor in the department of Rehabilitation Science at the University of
19 Oklahoma Health Sciences Center. She has a Ph.D. in pediatric physical therapy (with a minor
20 in family therapy) from Hahnemann University. Her research areas are in early identification of
21 children with or at risk for disabilities, efficacy of robotics in early mobility of young infants,
22 cultural and environmental influences on development, and measurement. Together with Dr.
23 Suzann Campbell and other colleagues, Dr. Kolobe has developed the Test of Infant Motor
24 Performance, for preterm infants up to 4 months post-term. The test has been normed and is
25 currently being used worldwide. For the past 4 years Dr. Kolobe has chaired the Research
26 Committee of the Section on Pediatrics, and more recently chaired a Task Force to develop a
27 Research Agenda for American Physical Therapy Association's Section on Pediatrics. In 2009
28 she was appointed to serve on the Scientific Review Committee for the NICHD/NIH. Dr.
29 Kolobe also brings extensive clinical experience in pediatrics and community-based
30 interventions. Over the past 30 years her roles in this area have ranged from direct patient care in
31 various settings, to clinical education, staff development, and consultant. Dr. Kolobe's
32 consultation roles have focused largely on program evaluation for community-based programs
33 that serve children and families with disabilities, and funded undergraduate and graduate training
34 programs. She currently serves on the Evaluation Committee for the Oklahoma SoonerStart
35 program, which is a statewide early intervention program funded through the Part C program of
36 Individual with Disabilities Education Amendment Act of 2004.

37
38 **Pamela Loprest** is a labor economist and Director of the Center on Income and Benefits at the
39 Urban Institute. She received her Ph.D. in economics from the Massachusetts Institute of
40 Technology. Her research focuses on low-wage labor markets and barriers to work among
41 disadvantaged populations and policies to address these issues. Dr. Loprest is a nationally known
42 expert in welfare policy and research. Her recent work examines how to structure programs and
43 policies to better support work among persons with disabilities and former welfare recipients
44 with work-related challenges. Past studies include examination of the Family and Medical Leave
45 Act, the role of employer accommodations, public policies to support job search and training for
46 persons with disability, and the impact of the Supplemental Security Income program on young

1 adult recipients transitioning to work. She is author of numerous journal articles and book
2 chapters, as well as three books.

3
4 **Kathryn E. Newcomer** is the Director of the Trachtenberg School of Public Policy and Public
5 Administration at the George Washington University. Dr. Newcomer earned a B.S. in education
6 and an M.A. in political science from the University of Kansas, and her Ph.D. in political science
7 from the University of Iowa. She teaches public and nonprofit program evaluation, research
8 design, and applied statistics. She routinely conducts research and training for federal and local
9 government agencies and nonprofit organizations on performance measurement and program
10 evaluation, and has designed and conducted evaluations for several U.S. federal agencies and
11 dozens of nonprofit organizations. Dr. Newcomer has published five books and numerous
12 articles in journals including the Public Administration Review. She is a Fellow of the National
13 Academy of Public Administration, and currently serves on the Comptroller General's Educators'
14 Advisory Panel. She served as President of the National Association of Schools of Public
15 Affairs and Administration (NASPAA) for 2006-2007. She received the Elmer Staats Award for
16 Achievements in Government Accountability, awarded by the National Capital Area Chapter of
17 the American Society for Public Administration, May 8, 2008. She has been a member of the
18 NRC Committee on Approaches for an Evaluation of the NIST/NRC Postdoctoral Research
19 Associateships Program, the NRC Review of United States Institute of Peace Senior Fellows
20 Program, and the NRC Committee on Laboratory Security and Personnel Assurance Systems for
21 Laboratories Conducting Research on Biological Select Agents and Toxins.

22
23 **Patricia M. Owens** is the senior disability expert for the Government Accountability Office.
24 Ms. Owens has over 30 years of experience in health and disability related programs and policy.
25 She has an unusual set of qualifications having held executive, policy development and
26 administrative positions in both the public and private disability sectors. Her experience serves
27 as the basis for in-depth understanding of the multidimensional and interactive nature of health
28 and disability in terms of social policy and risk management. She has consulted with both
29 private and public sector organizations on health and disability issues, programs and products.
30 Public sector groups include The Social Security Administration, The Veterans Administration,
31 The Urban Institute, The National Academy of Social Insurance (Board Member), Research on
32 Employment Policy, Rutgers Disability Income Studies and GAO. She helped UNUM, UK (an
33 insurance company in Great Britain) launch a study of the cost of disability in 2000-2001. Ms.
34 Owens is a member of The Board of Directors of Village Care of New York, a multi-million
35 dollar AIDS treatment network and community nursing and rehabilitation services provider for
36 persons with impairment. She was a member of the NRC-IOM Committee on Veterans'
37 Compensation for Posttraumatic Stress Disorder.

38
39 **Robert G. Radwin** is professor of the Department of Biomedical Engineering, a professor of
40 Industrial and Systems Engineering, and a professor in the Department of Orthopedics &
41 Rehabilitation at the University of Wisconsin-Madison. He has a Ph.D. in industrial and
42 operations engineering from The University of Michigan. He actively studies the recognition,
43 causes and control of musculoskeletal disorders in manual work. Dr. Radwin has received
44 numerous grants from government agencies, private foundations and industry. His research is
45 concerned with developing measurement and analytical methods for assessing exposure to
46 physical stress in the workplace; understanding ergonomics aspects of the design, selection,

1 installation and use of manually operated equipment including hand tools; and quantifying
2 functional deficits associated with musculoskeletal disorders and peripheral neuropathies. He is
3 a Fellow of the American Institute of Medical and Biological Engineers, the American Industrial
4 Hygiene Association, the Biomedical Engineering Society, the Ergonomics Society (UK), and
5 the Human factors and Ergonomics Society. He was a member of the NRC-IOM Panel on
6 Musculoskeletal Disorders and the Workplace and the NRC Committee on Human-Systems
7 Integration.

8
9 **Jeanne Rivard** is a Senior Program Officer. She earned a Ph.D. in Social Work at the
10 University of North Carolina at Chapel Hill where she received a National Research Service
11 Award from NIMH (F31, MH11552) to conduct her dissertation study investigating factors
12 promoting change in interagency collaboration. She also has a M.S.W. degree (University of
13 South Carolina) and an M.S.Ed. (Mount St. Mary's College, Los Angeles, CA). While on the
14 faculty of the Columbia University School of Social Work, her research included a
15 developmental study examining the implementation and intermediate outcomes of a trauma-
16 focused intervention for youth (R21 MH62896) and an evaluation of the implementation and
17 outcomes of an interagency initiative designed to integrate vocational and supportive housing
18 services for homeless persons with mental illness, substance abuse, HIV, and other disabilities.
19 Before coming to DBASSE she worked at the National Association of State Mental Health
20 Program Directors Research Institute where she led initiatives to promote the dissemination of
21 evidence-based practices; was a team leader on the national impact component of the cross-site
22 evaluation of the National Child Traumatic Stress Initiative, and coordinated pilot studies to
23 increase the utilization of multi-state administrative datasets to address mental health policy
24 questions.

25 **Tina Winters** is an Associate Program Officer. She has returned to the Academies to work with
26 the Committee on the External Evaluation of NIDRR and Its Grantees. Prior to rejoining the
27 Academies, she worked on an initiative to spread innovative health care practices and with the
28 coordinating center for a medical registry on islet cell transplantation. In her previous tenure at
29 the Academies, she worked with the Committee on Social Science Evidence for Use and has
30 supported numerous studies, including Scientific Research in Education, Knowing What
31 Students Know: The Science and Design of Educational Assessment, and the National Science
32 Education Standards.

33 **Matthew McDonough** is a Research Associate. Matt is a graduate of The George Washington
34 University with an M.A. in anthropology and a concentration in international development. In
35 five years working at the NRC he has staffed the Board on Life Sciences, the Board on
36 Behavioral, Cognitive, and Sensory Sciences, the Committee on Human-Systems Integration,
37 and the Board on Children, Youth, and Families. In addition to assisting with the work of
38 BBCSS and COHSI, he currently provides support to projects involving national security and
39 disability and rehabilitation research. He has supported such studies as *Guidelines for Human*
40 *Embryonic Stem Cell Research*, *Human-Systems Integration in the Design Process: A New Look*,
41 *Human Behavior in Military Contexts*, and *Early Childhood Assessment: Why, What, and How*.

1 **Mary Ellen O'Connell** is the Deputy Director of the Board on Behavioral, Cognitive and
2 Sensory Sciences and the Committee on Human-Systems Integration. Mary Ellen has a B.A.
3 (with distinction) from Cornell University and a Masters in the management of human services
4 from the Heller School for Social Policy and Management at Brandeis University. She has
5 served as study director for five consensus studies at the National Research Council: on
6 prevention of mental disorders and substance abuse, international education and foreign
7 languages, ethical considerations for research on housing-related health hazards involving
8 children, reducing underage drinking, and assessing and improving children's health. She also
9 served as study director for the Committee on Standards of Evidence and the Quality of
10 Behavioral and Social Science Research, a DBASSE-wide strategic planning effort; developed
11 standalone workshops on welfare reform and children and gun violence; and facilitated meetings
12 of the national coordinating committee of the Key National Indicators Initiative. She came to
13 DBASSE from the U.S. Department of Health and Human Services (HHS), where she spent
14 eight years in the Office of the Assistant Secretary for Planning and Evaluation, most recently as
15 director of state and local initiatives. Prior to HHS, she worked at the U.S. Department of
16 Housing and Urban Development on homeless policy and program design issues and for the
17 Commonwealth of Massachusetts as the director of field services.

18
19 **Barbara Wanchisen** is Director of the Board on Behavioral, Cognitive and Sensory Sciences
20 and the Committee on Human-Systems Integration. She received a B.A. in English and
21 Philosophy from Bloomsburg University in Pennsylvania, an M.A. in English from Villanova
22 University, and her Ph.D. in experimental psychology from Temple University. She is a long-
23 standing member of the Psychonomic Society, the Association for Behavior Analysis, and the
24 American Psychological Association. In January 2004, she became a Fellow of Division 25
25 (Behavior Analysis) of the American Psychological Association. She has served on the editorial
26 boards of the *Journal of the Experimental Analysis of Behavior* and *The Behavior Analyst* while
27 also serving as a guest reviewer of a number of other journals. From November 2001 until April
28 2008, Wanchisen was the executive director of the Federation of Behavioral, Psychological, &
29 Cognitive Sciences in Washington, DC. In 2004, she was instrumental in the founding of the
30 Federation's Foundation for the Advancement of Behavioral and Brain Sciences, a non-profit
31 organization that assumed the educational mission of the Federation. Previously, Wanchisen was
32 Professor in the Department of Psychology and Director of the college-wide Honors Program at
33 Baldwin-Wallace College, near Cleveland, Ohio.