

Institute on Disability / UCED

at the University of New Hampshire's
College of Health and Human Services

iod.unh.edu

2013 Inventory: Health-Related Initiatives

July 1, 2012 – June 30, 2013



Acknowledgements

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Available in alternative formats upon request.

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The IOD's initiatives in the area of health and public health aim to improve the health and well-being of individuals with disabilities and/or inherited (genetic) disorders. We accomplish this through a variety of grants, programs, and scholarly activities, including research, education and training, evaluation and consultation, technical assistance, and informing policy.

Many of these activities represent collaborations with university departments, public health officials, families, care-givers, primary and specialty health care providers, and other agencies within the state of New Hampshire, New England, and nationally.

Health-Focused Projects

A Three State Surveillance System for Rare Conditions (SSRC)

This project is a collaboration between three states (Kansas, South Carolina, and Colorado) with strong university-state government partnerships. Each state will compare the effectiveness of a passive and an active surveillance approach. Dr. Reichard will lead the Kansas team in establishing a state surveillance system for the conditions of spina bifida, Fragile X syndrome, and muscular dystrophy, modeled on the examples of the experiences of the other two states (South Carolina and Colorado).

Principal Investigator: Amanda Reichard, PhD

Data Source: Medicaid Claims, Vital Statistics, Birth Defects, and Kansas Children and Youth with Special Health Care Needs data

Disability & Public Health Project

The New Hampshire Disability & Public Health project aims to promote and maximize health, prevent chronic disease, and improve emergency preparedness in order to increase the quality of life among people with disabilities.

Principal Investigator: Charles Drum, MPA, JD, PhD

Website: iod.unh.edu/Projects/dph/project_description.aspx

Data Source: NH Behavioral Risk Factor Surveillance System, National Survey of Children with Special Health Care Needs, Integrated Disability Education and Awareness Program, U.S. Census Bureau

Health Disparities Project

The Health Disparities Project uses systematic scoping reviews and analysis of secondary data to develop a greater understanding of how health

Health-Related Initiatives Report Card

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disparities differ between different disability groups and will develop policy and programmatic recommendations based on these results.

Principal Investigator: Charles Drum, MPA, JD, PhD

Website: iod.unh.edu/Projects/health_disparities/project_description.aspx

Data Source: Medical Expenditure Panel Survey, Systemic Scoping Reviews of Clinical Preventive Services and Health Outcomes

Health Disparities & Intellectual Disability

Current research suggests that people with intellectual disabilities experience poorer health and that current public health and health care systems do not adequately monitor or address their needs. Health Disparities & Intellectual Disability expands upon current research by examining the factors associated with these disparities, in order to inform future changes to health policies, programs, and practices.

Principal Investigator: Andrew Houtenville, PhD

Website: iod.unh.edu/Projects/healthdisparities_id/project_description.aspx or www.researchondisability.org

Community Engagement Initiative (CEI) Knowledge Translation (KT) Research Project

Research on how knowledge translation happens -- that is, how research findings or research-based practices are understood and then applied in the field -- is critical, but it is also an emerging field. The purpose of the CEI KT Research Project is to investigate the knowledge transfer process by evaluating the impact of varying levels of technical assistance given to communities applying a community engagement methodology to increase the participation of people with disabilities in health care and recreation opportunities.

Principal Investigator: Charles Drum, MPA, JD, PhD

Website: <http://iod.unh.edu/Projects/rrtc-cl/r-10.aspx>

Data Source: Primary Data Collection

Obesity and Disability Project – Adapting Community-Based Obesity Reducing National Strategies Project, Public Policy Expert Panel, Chair

The aim of the Obesity and Disability project is to develop a set of methods and criteria that can be used to systematically identify, adapt, and modify recognized evidence-based obesity prevention and reduction strategies and programs for youth and young adults with disabilities from culturally diverse backgrounds. The purpose of the Public Policy Expert Panel is to identify adaptive strategies from a public policy perspective to promote inclusion in community health promotion programs for youth with disabilities.

Principal Investigator: Charles Drum, MPA, JD, PhD

Website: http://iod.unh.edu/Projects/ObesityandDisability/Project_Description.aspx

Data Source: Expert Opinion

New England CCHD Newborn Screening Project

The purpose of the New England CCHD Newborn Screening Project is to expand existing infrastructure among public health departments and birthing facilities to develop processes for Critical Congenital Heart Disease (CCHD) screening that set the stage for improved health outcomes for newborns. A multi-disciplinary team will share resources and expertise to develop screening protocols, educational materials and programs, and perform program evaluation.

Principal Investigator: Monica McClain, PhD

Website: iod.unh.edu/Projects/newengland_cchd/project_description.aspx

Data Source: Primary Data Collection

New England Genetics Collaborative (NEGC)

The New England Genetics Collaborative provides a regional infrastructure of public and private health genomics expertise to improve, expand, strengthen and evaluate access to a system of genetic services, and the quality of those services, to improve health outcomes for children, youth, and adults across their life course.

Principal Investigator: Monica McClain, PhD

Website: iod.unh.edu/Projects/negc/project_description.aspx or www.negenetics.org

Data Source: 2 Quality Improvement Projects, Health Access and Financing Survey, and GEMSS

Genetic Education Materials for School Success (GEMSS)

The aim of GEMSS is to assure all children with genetic health conditions succeed in school-life.

Principal Investigator: Monica McClain, PhD

Website: www.gemssforschools.org/

Data Source: Medical Literature Review, Educational Review, Family Review

New Hampshire Leadership Education in Neurodevelopmental Disabilities Program (NH LEND)

The purpose of NH LEND is to improve the health of children and youth with neurodevelopmental disabilities by preparing leaders to enter the field of maternal and child health. Trainees from a wide variety of professional disciplines engage in 300 hours of training related to interdisciplinary, family-centered, culturally competent systems of care for children and youth with developmental disabilities and their families.

Principal Investigator: Betsy P. Humphreys, M.Ed., PhD

Website: iod.unh.edu/Projects/nh-lend/program_description.aspx or www.mchlend.unh.edu

Data Source: National Survey of Children with Special Health Care Needs

Seacoast Child Development Clinic

The Seacoast Child Development Clinic provides family-centered and culturally sensitive interdisciplinary evaluation and consultation to assist families of children who have developmental challenges to make informed decisions regarding medical, developmental, and educational needs. The Seacoast Child Development Clinic is a clinical training site for the NH LEND training program.

Website: iod.unh.edu/Projects/seacoast-clinic/program_description_funding.aspx or www.seacoastclinic.unh.edu/

New Hampshire Children's Mental Health Competencies

The New Hampshire Children's Mental Health Competencies project is designed to assist New Hampshire's community mental health center children's directors, family organizations, and the Department of Health and Human Services to develop a set of core competencies designed to enhance the ability of the workforce to provide evidence-informed and best practices in children's mental health.

Principal Investigator: JoAnne Malloy, PhD

Website: iod.unh.edu/Projects/nhcmh_competencies/project_description.aspx

RENEW

RENEW is a structured school-to-career transition planning and individualized wraparound process for youth with emotional/behavioral challenges. Developed in 1996 by staff at the IOD, RENEW is being provided by schools, community mental health centers, community-based providers, and IOD staff members to youth. The model focuses on supporting each youth to design and pursue a plan for the transition from school to adult life. RENEW has substantially increased the high school

completion, employment, and post-secondary education participation rates among our most vulnerable youth.

Principal Investigator: JoAnne Malloy, PhD

Website: iod.unh.edu/Projects/renew/renew_main.aspx

NH Children's Behavioral Health Workforce Development Network.

This project addresses the workforce development needs of the children's behavioral health workforce within a System of Care framework. The project involves coordination and development of training and coaching network across diverse, cross-disciplinary providers and family stakeholders who are in the children's behavioral health system. The training network is working within 4 focus areas: pre-service learning, in-service learning, evidence-based practices, and family-driven wraparound practice.

Principal Investigator: JoAnne Malloy, PhD

Website: http://iod.unh.edu/Projects/NH_childrens_bh_pd_network/Project_Description.aspx

Who Cares About Kelsey?

IOD Filmmaker-in-Residence Dan Habib's newest film project "Who Cares About Kelsey?" documents the lives of students with emotional/behavioral challenges, and shows innovative educational approaches that help these students to succeed – while improving the overall school culture and climate.

Principal Investigator: Dan Habib

Website: iod.unh.edu/Projects/pbisfilm/preview.aspx or www.whocaresaboutkelsey.com

Center for START Services

The Center for START (Systematic, Therapeutic, Assessment, Respite, and Treatment) Services provides consultation and training in crisis prevention, management, and support for

individuals with intellectual disabilities and behavioral health needs. The mission of the Center for START Services is to enhance local capacity and provide collaborative, cost-effective support to individuals and their families through exemplary clinical services, education and training, with close attention to service outcomes.

Principal Investigator: Joan Beasley, PhD

Website: iod.unh.edu/Projects/start/description_history.aspx or www.centerforstartservices.com/

Data Source: START Information Reporting System

IC-RRTC: The Rehabilitation Research and Training Center on Individual-Level Characteristics Related to Employment among Individuals with Disabilities

IC-RRTC is generating new knowledge about the role of individual characteristics (health, demographic, human capital, social capital, and environmental characteristics) on employment outcomes. Despite the ADA and advances in medicine and technology, people with disabilities, as a group, have become economically less self-sufficient over the last few decades. For people with disabilities, employment rates have declined, reliance on public benefits has increased, and household incomes have fallen further behind those of other households. In addition, there are substantial disparities in employment outcomes within the population with disabilities. The IC-RRTC works toward improving strategies and interventions designed to foster better employment outcomes for the various subpopulations of people with disabilities.

Principal Investigator: Andrew Houtenville, PhD

Website: iod.unh.edu/Projects/ic-rrtc/about.aspx or www.researchondisability.org/ic-rrtc

Data Source: American Community Survey, Medical Expenditures Panel Survey, Current Population Survey

StatsRRTC: The Rehabilitation Research and Training Center on Disability Statistics and Demographics

StatsRRTC aims to improve knowledge about and access to existing data, and generate the knowledge needed to improve future disability data collection and dissemination. StatsRRTC's goal is to foster evidence-based decision making by people with disabilities and their families, advocates, policymakers, program administrators, service providers, and researchers by making data widely available and accessible. As part of project activities, StatsRRTC produces the "Annual Disability Statistics Compendium," a document which aggregates data on disability prevalence, employment, poverty, health and health insurance coverage, health care programs like Medicare and Medicaid, vocational rehabilitation, and several other topics from a number of federal sources.

Principal Investigator: Andrew Houtenville, PhD

Website: iod.unh.edu/Projects/StatsRRTC/about.aspx or www.researchondisability.org/statsrrtc or www.disabilitycompendium.org/

Data Source: American Community Survey, Current Population Survey, Behavioral Risk Factor Surveillance System

Rehabilitation Research and Training Center on Employment Policy and Measurement (EPM-RRTC)

The EPM-RRTC is investigating the impact of federal and state policies and programs on employment among persons with disabilities and facilitating the translation of research findings to guide policy making and program administration.

Principal Investigator: Andrew Houtenville, PhD

Website: iod.unh.edu/Projects/epm_rrtc/project_description.aspx or www.researchondisability.org/

Data Source: Current Population Survey, American Community Survey, Survey on Income and Program Participation

Health-Focused Programs of Study

New Hampshire Leadership Education in Neurodevelopmental Disabilities Program (NH LEND)

The NH LEND program is Maternal and Child Health workforce development program. Graduate level traineeships require a minimum commitment of 300 hours over a 9-month period. The curriculum follows the academic calendar and includes coursework and experiences working with faculty, families, community partners, and legislators in New Hampshire and nationally. NH LEND activities are organized into three core areas; academic coursework, leadership skill development and clinical training. Each core area represents approximately 100 hours of direct contact time. The curriculum and activities are designed to support trainees' ability to move into professional leadership roles in NH communities.

Health-Focused Academic Coursework

HHS 444 - The Right to be Disabled in the Extreme Makeover Society

Explores how society's view of disability, its "construction," is influenced by a variety of cultural variables and the implications of that construction on institutions such as medicine and health care, education, the arts, the legal system, architecture and engineering, etc.

HHS 798/898 - Special Topics in Neurodevelopmental Disorders (LEND) Seminar

The LEND seminar is a survey course focused on the acquisition of a broad understanding

of knowledge of MCH, Title V/Public Health Program & Policies for children with neurodevelopmental and related disabilities. This includes interdisciplinary team skills; integration of services across sectors (education, health, Part B & C, and transitions); cultural competency and family-centered services; life course and social determinants of health; leadership skills (refer to MCH Leadership Competencies, Version 3.0); and communication skills (e.g., verbal, written, conflict resolution).

Health-Focused Guest Lectures

Bimbo, L. Recreation Services for Individuals with Intellectual Disabilities. RMP 501 – Recreation Services for Individuals with Disabilities, University of New Hampshire, Spring 2012.

Bimbo, L. Recreation Services for Individuals with Intellectual Disabilities. RMP 501 – Recreation Services for Individuals with Disabilities, University of New Hampshire, Spring 2013.

Cloutier, H. Transition Planning. SW 812 – Understanding Developmental Disabilities, University of New Hampshire, Spring 2012.

Dillon, A. Family-Centered Care for Children with Chronic Health Conditions. EDUC 760/860 – Introduction to Young Children with Special Needs, University of New Hampshire, Fall 2012.

Dillon, A. Family-Centered Practice. HHS 898 – Topics in Neurodevelopmental Disabilities (LEND Seminar), University of New Hampshire, Fall 2012.

Dillon, A. Person-Centered Planning for Children. SW 812 – Understanding Developmental

Disabilities, University of New Hampshire, Spring 2012.

Drum, C. E. Disability & Health Disparities. HHS 898 – Topics in Neurodevelopmental Disabilities (LEND Seminar), University of New Hampshire, Fall 2012

Drum, C.E. Disability and Health. HHS 401 - U.S. Healthcare Systems, Spring 2013.

Fox, S. Aging and Disability. SW 812 – Understanding Developmental Disabilities, University of New Hampshire, Spring 2012.

Fox, S. Ethics and Disability. BIOL 4 – Genes and Society, Dartmouth Medical School, Spring 2012.

Fox, S. Where Do We Go From Here? A Public Policy Framework for Long Term Care Services. Presentation to the NH Legislature, Concord, NH, February 2013.

Fox, S. Ethics and Disability: Institutionalization to Inclusion. Guest Lecture in BIOL 4 Class, Genes

and Society, Dartmouth Medical School, Hanover, NH, April 2013.

Malloy, J., Interagency and Community Systems for Transition (SPED859), University of Kansas, Spring 2013.

McClain, M.R., Genetics Condition through the Life Course, HHS 898, Topics in Neurodevelopmental Disabilities (LEND Seminar), January 2012.

McClain, M.R., Genetics Condition through the Life Course, HHS 898, Topics in Neurodevelopmental Disabilities (LEND Seminar), January 2013.

McClain, M.R., Ethical, Legal, and Social Implications of Genetic Testing, GEN 706, Human Genetics, November 2012.

Smith, J. Family Perspectives on ASD Diagnosis and Securing Services (2 lectures). COMM 916 – Autism Spectrum Disorders, University of New Hampshire, Fall 2012.

Sonnenmeier, R. Developmental Screening. SW 812 – Understanding Developmental Disabilities, University of New Hampshire, Spring 2012.

Health-Focused Peer Review and Other Publications

Peer-Reviewed Articles (12)

Andresen, E., Peterson-Besse, J., Krahn, G., Walsh, E., Horner-Johnson, W., Iezzoni, L., & the Expert Panel on Disability and Health Disparities [C. Drum & G. Fujiura] Pap, mammography, and clinical breast exam screening among women with disabilities: a systematic review (in press). *Women's Health Issues*.

Charlot, L. & Beasley, J.B. (2013). Intellectual Disabilities and Mental Health: United States–Based Research, *Journal of Mental Health Research in Intellectual Disabilities*, 6:2, 74-105

Burkhauser, R., Houtenville, A., & Tennant, J. (2012). Capturing the elusive population of people with disabilities. *Journal of Disability Policy Studies*. Interim online location: <http://dps.sagepub.com/content/early/2012/05/30/1044207312446226>.

Drum, C.E. (in press). The dynamics of disability and chronic conditions. *Disability and Health Journal*.

Drum, C.E., Walsh, E., & Horner-Johnson, W. (2012). Construction and validation of the Outpatient Health Care Usability Profile (OHCUP). *Disability and Health Journal*, 5(4), 292-297.

Fujiura, G. & the RRTC Expert Panel on Health Measurement (E. Andresen, B. Cardinal, C. Drum, T. Hall, W. Horner-Johnson, G. Krahn, M. Nosek, Jana Peterson-Besse, & R. Suzuki) (2012). Self-reported health of people with intellectual disability. *Intellectual and Developmental Disabilities*, 50(4), 352-369.

Hagner, D., Kurtz, A., May, J. & Cloutier, H. (in press). Person-centered planning for transition-aged youth with autism spectrum disorders. *Journal of Rehabilitation*.

Horner-Johnson, W., Dobberton, K., Lee, J.C., Andresen, E., & the Expert Panel on Disability and Health Disparities [C. Drum, G. Fujiura, G. Krahn, & L. Iezzoni]. (in press). Disparities in chronic

conditions and health status by type of disability. *Disability and Health Journal*.

Houtenville, A. J. & Brucker, D. L. (in press). Participation in safety-net programs and the utilization of employment services among working-age persons with disabilities. *Journal of Disability Policy Studies*.

Houtenville, A. & Kalargyrou, V. (2012). People with disabilities: Employers' perspectives on recruitment practices, strategies, and challenges in leisure and hospitality. *Cornell Hospitality Quarterly*, 53(1) 40-52.

Malloy, J. (in press). Person centered planning and individualized teams: How the RENEW model supports transition-age youth with emotional and behavioral challenges. *Report on Emotional and Behavioral Disorders in Youth*.

Malloy, J. (2013). The RENEW Model: Supporting Transition-Age Youth With Emotional and Behavioral Challenges. *Report on Emotional and Behavioral Disorders in Youth*. 13(2), 38-46.

Books and Book Chapters (5)

Burkhauser, R., Houtenville, A., & Tennant, J. (in press). Comparing Levels and Trends in the Prevalence, Employment and Program Participation Rates of Working-Age People with Disabilities. In M. C. Daly, K. Couch, & J. M. Zissimopoulos (Eds.), *Unexpected Lifecycle Events and Economic Well-Being: The Roles of Job Loss, Disability, and Changing Family Structure*. Palo Alto, CA: Stanford University Press.

Crais, E., Humphreys, B. P., McComish, C., & Wilson, K. (in press). Additional Developmental Assessments and Treatments. In D. Kober & D. Treadwell Deering (Eds.), *Handbook of Autism – A Concise Guide*.

Eber, L., Malloy, J., Rose, J., & Flamini, A. (in press). School-based wraparound for adolescents: The RENEW model for transition-aged youth with or at-risk of EBD. In H. Walker & F. Gresham (Eds.), *Evidence-Based Practices for Addressing School-Related Behavior Problems and Disorders*.

University of Oregon and Louisiana State University.

Hagner, D., Dague, B. & Phillips, K. (in press). Supporting inclusion into workplace cultures. In L. O'Hearn (Ed.) *Way leads on to way: Paths to employment for people with intellectual disability*. Washington DC: American Association on Intellectual and Developmental Disability.

Willkomm, T. (2013). *Assistive Technology Solutions in Minutes II- Ordinary Items, Extraordinary Solutions*, Durham, NH: University of New Hampshire, Institute on Disability.

Training Curricula (2)

Dillon, A. (2012). *New Hampshire Leadership Series: Group Leader Guide*. Durham, NH: University of New Hampshire, Institute on Disability.

Malloy, J., Drake, J., Cloutier, H., & Couture, D. (2012). *RENEW Facilitator's Manual: A Secondary Transition Model for Youth and Young Adults*, Second Edition. Durham, NH: University of New Hampshire, Institute on Disability.

Other Dissemination Materials (17)

Antal, P. (2012). *New Hampshire Public Mental Health Consumer Survey Project: Summary of Findings*. Durham, NH: University of New Hampshire, Institute on Disability.

Antal, P. (2012). *New England Genetics Collaborative, Results of the Stakeholder Survey for Project Year Four*. Durham, NH: University of New Hampshire, Institute on Disability.

Antal, P. (2012). *New England Genetics Collaborative, Annual Evaluation Report for Project Year Four*. Durham, NH: University of New Hampshire, Institute on Disability.

Antal, P. (2012). *Leadership in Neurodevelopmental Disabilities Program Year 1 Evaluation Report*. Durham, NH: University of New Hampshire, Institute on Disability.

Antal, P. (2012). *Leadership in Neurodevelopmental Disabilities Program Year 1 Faculty Survey Report*. Durham, NH: University of New Hampshire, Institute on Disability.

Antal, P. (2012). *Leadership in Neurodevelopmental Disabilities Program Year 1 Stakeholder Survey Report*. Durham, NH: University of New Hampshire, Institute on Disability.

Antal, P. (2012). *Leadership in Neurodevelopmental Disabilities Program Year 1 Trainee Survey Report*. Durham, NH: University of New Hampshire, Institute on Disability.

Beasley, J. (2012). *START Team Clinical Manual*. Durham, NH: University of New Hampshire Institute on Disability.

Beasley, J. (2012). *START Team Therapeutic Respite Manual*. Durham, NH: University of New Hampshire Institute on Disability.

Beasley, J. (2012). The United States V The State of Georgia 2010 Olmstead Settlement Agreement: U.S. public policy implications. *The NADD Bulletin* (16) 2.

Houtenville, A. & Ruiz, T. (2012). *2012 Annual Disability Statistics Compendium*. Durham, NH: University of New Hampshire, Institute on Disability.

McSheehan, M., Jorgensen, C., Sonnenmeier, R., & Schuh, M. (in press). *Essential Best Practices in Inclusive Schools*. Durham, NH: University of New Hampshire, Institute on Disability.

Moser, J. (2012). Improving Preparedness and Flexibility in Web-Based Trainings for North American START Teams. *The NADD Bulletin* 15(5), 89-90.

Willkomm, T. A.T. *Pad Stand* – Patented March 19, 2013

Willkomm, T. The Future of iPads and iPhone for People with Disabilities, *ATIA Newsletter*

Willkomm, T. *The Eileen Series: The Traveling Eileen; Mini Lean, Electra-Lean, Slanta-Lean, Scana-*

Lean, Seata-Lean, Presento-Lean, Jumbo-Leana, Flippa-Lean, Waista-Lean, and the Clipa-Lean

Willkomm, T. A.T. *Plate Plus Weight – Hands Free Mounting Solutions*



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