Institute on Disability / UCED

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

2013 Inventory: Health-Related Initiatives
July 1, 2012 – June 30, 2013
Acknowledgements
This report was prepared by Charles Drum, MPA, JD, Ph.D., at the Institute on Disability, University of New Hampshire. The Institute on Disability is directed by Charles Drum and guided by a Consumer Advisory Council.

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](http://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 disparities exist for persons with disabilities.

**Health-Related Initiatives Report Card**

**Projects:** 19

**Teaching Activities:** 21
**Programs of Study:** 1
**UNH Courses:** 2
**Guest Lectures:** 18

**Publications and Creative Work:** 36
**Peer-Reviewed Articles:** 12
**Books and Book Chapters:** 5
**Training Curricula:** 2
**Other Dissemination Materials:** 17
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:** [http://iod.unh.edu/Projects/rrtc-cl/r-10.aspx](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/rrtc-cl/r-10.aspx](http://iod.unh.edu/Projects/rrtc-cl/r-10.aspx)

**Data Source:** Primary Data Collection

**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/health_disparities/project_description.aspx](http://iod.unh.edu/Projects/health_disparities/project_description.aspx) or [www.researchondisability.org](http://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:** [iod.unh.edu/Projects/newengland_cchd/project_description.aspx](http://iod.unh.edu/Projects/newengland_cchd/project_description.aspx)

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

**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](http://iod.unh.edu/Projects/newengland_cchd/project_description.aspx)

**Data Source:** Expert Opinion
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

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](http://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](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](http://iod.unh.edu/Projects/pbisfilm/preview.aspx) or [www.whocaresaboutkelsey.com](http://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](http://iod.unh.edu/Projects/start/description_history.aspx) or [www.centerforstartservices.com/](http://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](http://iod.unh.edu/Projects/ic-rrtc/about.aspx) or [www.researchondisability.org/ic-rrtc](http://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/


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
Explains 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


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.


Drum, C. E. Disability & Health Disparities. HHS 898 – Topics in Neurodevelopmental Disabilities (LEND Seminar), University of New Hampshire, Fall 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
Health-Focused Peer Review and Other Publications

Peer-Reviewed Articles (12)


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


**Books and Book Chapters (5)**


University of Oregon and Louisiana State University.


**Training Curricula (2)**


**Other Dissemination Materials (17)**


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

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