

## 2013 ANNUAL REPORT





















### INSTITUTE ON DISABILITY/UCED

A UNIVERSITY CENTER FOR EXCELLENCE IN DISABILITY AT THE UNIVERSITY OF NEW HAMPSHIRE

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 $\hbox{@}$  January 2014. Institute on Disability. University of New Hampshire.

Available in alternative formats upon request.

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Dear Friends and Colleagues,

It is a pleasure to present the Institute on Disability (IOD) annual report for FY 2013. The report summarizes Institute faculty and staff accomplishments throughout the fiscal year as we work to further our mission to promote full access, equal opportunities, and participation for all persons by strengthening communities and advancing policy and systems change, promising practices, education, and research.

There is no greater asset to an organization than its people. This is particularly true at the IOD. In FY '13, our staff grew to an all-time high of 107 employees. Although the quantity alone does not reflect the extraordinary individual talents and commitments by each staff member, it does however demonstrate the relevance and quality of our work and



the continued expansion of our reach and impact, particularly in a time of national economic challenges and shifting policy landscapes.

Fiscal year 2013 represents the last of a 4-year strategic planning cycle during which a number of strategic initiatives were realized including the adoption of "priority areas" in inclusive education, health and genetics, community living, and assistive technology. Additionally, as this report presents, the IOD has placed particular emphasis on expanding engagement with other organizations in equitable partnerships; ensuring prudent and effective management of precious IOD resources; increasing IOD contributions to new knowledge, best practices, and public policy; and developing strategies to maximize our financial strength and sustainability. These changes were designed to align not only with IOD strengths and areas of opportunity, but with emerging national, regional, and state priorities in the field of disabilities.

In the coming months, we will once again undertake the task of planning for our future and develop a new 3-year Strategic Plan that will prioritize our work through 2017. As in the past, it will be a journey of challenge and discovery, commitment and collaboration, inclusiveness and excellence, and I look forward to sharing the experience with you.

Thank you for your ongoing support and partnership.

Charles Drum

Sincerely,

Charles E. Drum, MPA, JD, PhD

Director, IOD & Professor of Health Management and Policy

#### **ABOUT THE INSTITUTE ON DISABILITY**

The Institute on Disability was established in 1987 to provide a university-based focus for the improvement of knowledge, policies, and practices related to the lives of people with disabilities and their families and is New Hampshire's University Center for Excellence in Disability (UCED). Located within the University of New Hampshire, the IOD is a federally designated center authorized by the Developmental Disabilities Act. Through innovative and interdisciplinary research, academic, service, and dissemination initiatives, the IOD builds local, state, and national capacities to respond to the needs of individuals with disabilities and their families.

#### MISSION

The IOD promotes full access, equal opportunities, and participation for all persons by strengthening communities and advancing policy and systems change, promising practices, education, and research.

#### **VISION**

The IOD envisions a future where all people, including those living with disabilities, are fully engaged members of communities and where culturally appropriate supports that lead to independence, productivity, and a satisfying quality of life are available to individuals and families across the life span.

#### A University Center for Excellence in Disability

The IOD is a member of the Association of University Centers on Disabilities (AUCD), a network of 67 university-based centers located in every state and territory in the United States. These centers are designed to facilitate the flow of disability-related information between communities and universities.

Centers work with people with disabilities, members of their families, state and local government agencies, and community providers on projects that offer training, technical assistance, service, research, and other resources, with a focus on building the capacity of communities to sustain all their citizens.



Since 1963, centers have worked toward a shared vision that foresees a nation in which all Americans, including Americans with disabilities, participate fully in their communities. Independence, productivity, and community inclusion are key components of this vision.

For more information, visit <u>www.aucd.org</u>.

### RESEARCH

The IOD makes significant contributions to the body of knowledge related to disability through its research and evaluation. Whether faculty and staff are collecting and analyzing data, facilitating focus groups, conducting model demonstration projects, or evaluating project outcomes, IOD research is informing the services, systems, and policies that impact the lives of individuals with disabilities. IOD Research in 2013 included 139 conference presentations with 106 being presented to a national or international audience.

## Program Spotlight: Annual Disability Statistics Compendium

The Annual Disability Statistics
Compendium serves as a single source for disability data "collected" from various federal agencies. In its fifth year of being produced by the Rehabilitation Research and Training Center on Disability Statistics and Demographics (StatsRRTC), the compendium allows people working on legislative and other matters relating to persons with disabilities to access statistics to support and shape decision making.

The Compendium's annual release takes

# RESEARCH BY THE NUMBERS...

- 19 Peer-Reviewed Articles
- 7 Books & Book Chapters
- 24 Other Research Products
- UNH's I<sup>st</sup> Design Patent for Dr. Therese Willkomm's A.T. Pad Stand

place on Capitol Hill in Washington, DC, and allows disability advocates, policymakers, and researchers the chance to come together and highlight research, issues, and policies which can better serve people with disabilities. Individuals may participate in person or watch live via webcast. You can access and explore the data year-round at www.DisabilityCompendium.org.

To learn more about the IOD's research projects, visit:
iod.unh.edu/research



### **A**CADEMICS



and Disability Studies/UCEDD at the University of Maine. It prepares leaders to enter the field of maternal and child health

> with the overall goal of improving the system of care for children and youth with neurodevelopmental disabilities. Since 1993, the NH LEND program has trained over 250 leaders in the field of developmental disabilities.

The NH LEND program is a workforce development program

that provides a minimum commitment of 300 hours of graduate-level training over a nine-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 around the nation. 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 New Hampshire and Maine communities.

NH LEND is funded through a grant from the Maternal and Child Health Bureau, Health Resources and Services Administration (HRSA) and is a part of a national network of 43 programs across the country.

The IOD is dedicated to preparing leaders in disability-related fields through university academics. IOD faculty and staff design and implement innovative learning experiences, interdisciplinary teaching models, and programs of study that incorporate universal design principles, include the perspectives of self-advocates, and employ a variety of instructional methods and formats.

#### Program Spotlight: NH LEND

The New Hampshire Leadership Education in Neurodevelopmental and Related Disabilities Program (NH LEND) is a collaboration between the Geisel School of Medicine at Dartmouth College, the Institute on Disability/UCED at the University of New Hampshire, and the Center for Community Inclusion

# ACADEMICS BY THE NUMBERS...

- 5 Training Curricula
- 22 UNH Courses
- 16 Guest Lectures
- 8 Programs of Study



### COMMUNITY SERVICE

The IOD supports the efforts of consumers and professionals to create more inclusive communities by providing local, regional, and national services that represent best practices and include:

- Offering professional development that is evidence-based, progressive, and culturally relevant
- Training tomorrow's leaders in disability-related fields
- Providing technical assistance to improve organizational and community capacities to include all citizens
- Serving as a resource for policy makers
- Providing interdisciplinary evaluation and consultation to families of children with disabilities

## Program Spotlight: The Center for START Services

The Center for START (Systemic, Therapeutic, Assessment, Respite & Treatment) Services is a national initiative that strengthens service efficiencies and outcomes for individuals with intellectual and developmental disabilities and behavioral health needs in the community. Driven by a person-centered approach in the context of the system of support, the START model offers proactive, clinically-based consultation and training for crisis prevention and intervention.

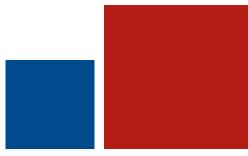
To learn more about the services the IOD provides, visit:

iod.unh.edu/services

# COMMUNITY SERVICE BY THE NUMBERS...

- 54 Events
- 2,829 Participants
- Satisfaction Rating of 3.39 out of 4.0.

The Center for START Services provides technical support, clinical expertise, and training and consultation services. START is currently being implemented in 25 U.S. States. Four states-- Arkansas, North Carolina, New Hampshire, and Virginia—have implemented it statewide. Over the past year, both New Hampshire and Ohio have moved towards providing lifespan services.





### **DISSEMINATION**

Through active and strategic information sharing, the IOD raises awareness and bridges the gap between disability research and practice. The IOD makes use of a variety of tactics, including traditional and emerging media, with the goal of maximizing the reach, accessibility, and impact of its resources.

In response to the increased use of online resources by the disability community, the IOD worked to strengthen its capacity to disseminate information electronically in FY '13. In addition to making significant investments in social media, the IOD hired a full-time web designer to manage its numerous websites and make improvements to digital communications. The IOD continued to produce and disseminate high quality print materials including the 2nd Annual Disability Statistics Compendium, a report and summary brief on the New Hampshire's Community Mental Health System, and an organizational curriculum vitae.

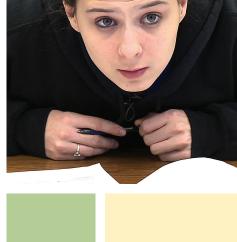
# Program Spotlight: Who Cares About Kelsey?

When Kelsey Carroll entered high school, she was a more likely candidate for the juvenile justice system than graduation.

# DISSEMINATION BY THE NUMBERS...

- 67,321 Website Visits
- I,376 Bookstore Orders
- 1,415 Digital Downloads
- 1,733 Facebook Followers

Diagnosed with ADHD and carrying the emotional scars of homelessness and abuse--as well as the actual scars of repeated self-mutilation--Kelsey was volatile, disruptive and, by her own admission, "not a nice person" to be around. During Kelsey's sophomore year, new school leadership



at Somersworth High School
implemented Positive Behavioral
Interventions and Supports and
RENEW-- a youth-directed planning process
developed by the IOD's JoAnne Malloy--to
improve the school's culture and reduce the
dropout rate.

The story of Kelsey's transformation from a defiant "problem student" to a motivated and self-confident young woman is documented by IOD Filmmaker in Residence, Dan Habib, in the film Who Cares About Kelsey?

Since its premiere, Who Cares About Kelsey? has screened at 11 film festivals and won Best Feature at the 2012 Lights. Camera. Help. Film Festival. During FY 2013, the film was screened 67 times across the United States and was broadcast on public television stations across the U.S. and Canada in the fall.



The IOD aligns its projects and strategic initiatives with current and emerging national, regional, and state priorities related to individuals with disabilities. A majority of IOD grants and programs are concentrated within the following areas:

#### **Assistive Technology**

Assistive technology (AT) is integral to the daily lives of many individuals with disabilities. The IOD continuously develops and expands its services and training in this area and is actively partnering on campus, throughout the state, and nationally to promote access to AT solutions and services.

#### PROGRAM SPOTLIGHT: [AT]CONNECTS

A National Public Assistive Technology Internet Site, AT Connects aims to provide guidance, news, information and to be a gateway to the various projects and programs funded by the AT Act in the states and territories. It provides resources for employers, highlights AT programs across the country, AT-related news items, and information on how individuals can use AT. AT Connects is a joint effort between SilverTech Inc. and the University of New Hampshire. You can visit the site at www.atconnects.com.

#### PROGRAM LIST

Assistive Technology in New Hampshire
(ATinNH)
AT Connects
getATstuff



#### **COMMUNITY LIVING**

Community living encompasses a broad range of IOD systems-change efforts related to adults and long-term services and supports including employment, housing, transportation, person-centered planning, aging, and direct care. The IOD offers well-researched and practical assistance that supports thoughtful program and public policy design for adults with disabilities and those aging into disabilities.

#### PROGRAM SPOTLIGHT: DIRECT CONNECT

DirectConnect was a collaborative initiative of the IOD and the Institute of Health Policy and Practice at UNH, funded by the US Department of Labor, and designed to recruit, train, and retain direct care workers in home and community based care settings. The project far exceeded its performance outcome goal of training 1,100 participants. Over the three years of the project 2,476 participants enrolled in the project, with 1,692 completing at least one training. 3,289 credentials were awarded. 2,052 of the participants were incumbent workers who received training to improve their job skills and 283 out of 418 participants who were unemployed found employment as a direct care worker as a result of the program.

#### PROGRAM LIST

NH Balancing Incentive Program

Center on Aging and Community Living

DirectConnect

Employment and Asset Development Resource Network (EARN)

**Employment Consultant Training** 

EPM-RRTC: Rehabilitation Research and Training Center on Employment Policy

Family-Centered Transition Planning

IC-RRTC: Rehabilitation Research and Training Center on Individual-Level Characteristics and Employment

NH Children's Behavioral Health Workforce Development Network

NH Children's Mental Health Competencies

NH Health Professional Opportunity Project

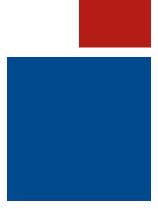
NH Leadership Series

Resources, Employment, Assets and Learning for Persons with Disabilities Opportunities Study

RTC-CL: Research and Training Center on Community Living

The Center for START Services

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





#### **INCLUSIVE EDUCATION**

When students with disabilities are provided appropriate instruction and supports, they can learn the general education curriculum, effectively communicate, have meaningful social relationships, and graduate from high school. The IOD partners with educators, administrators, and policy makers to develop and deliver the tools necessary for every student to be a fully participating member of the classroom.

PROGRAM SPOTLIGHT: RENEW

RENEW (Rehabilitation for Empowerment, Natural Supports, Education, and Work) is a structured school-to-career transition planning and individualized wraparound process for youth and their families who are most at-risk of experiencing poor educational and employment outcomes. In December 2012, RENEW was named to the Social Impact 100 of the Social Impact Exchange. Modeled on aspects of the S&P 500, the S&I 100 highlights organizations that consistently deliver impact. In May, RENEW's Director, JoAnne Malloy, presented at a legislative

briefing for members of Congress and their staff. Its impact is also highlighted in the documentary *Who Cares About Kelsey?* 

#### PROGRAM LIST

APEX: Achievement in Dropout Prevention and Excellence

Act Early

Genetic Education Materials for School

I Am Norm

**Including Samuel** 

National Center and State Collaborative

NH Augmentative and Alternative Communication (AAC) Initiative

NH RESPONDS

**RENEW** 

**SWIFT** 

Who Cares About Kelsey?



#### **HEALTH & GENETICS**

Health initiatives at the IOD aim to improve the health and well-being of individuals with disabilities and/or inherited (genetic) disorders. Work in this area includes a variety of activities and projects focusing on access to and the improvement of appropriate and quality health care.

## PROGRAM SPOTLIGHT: GEMSS FOR SCHOOLS

In Winter 2012, the IOD's New England Genetics Collaborative launched a new website, Genetics Education Materials for School Success (GEMSS), to provide educators, other school personnel, and parents with a "one stop shop" of useful tools and tips for support of students with genetic conditions throughout the school day. GEMSS provides practical guidance for educational teams in an easily-accessible continually-updated online format. Conditions and their symptoms are introduced through a brief description in plain language and visitors can also access strategies for addressing the unique needs of the condition.

#### PROGRAM LIST

Community Engagement Initiative Knowledge Translation Research Project

Seacoast Child Development Clinic

Disability & Public Health Project

Health Disparities & Intellectual Disability
Project

Health Disparities Project

Maternal Infant and Early Childhood Home Visiting Evaluation

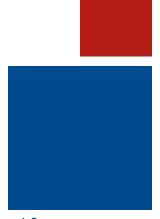
New England CCHD Newborn Screening Project

New England Genetics Collaborative

NH LEND: New Hampshire Leadership Education in Neurodevelopmental and Related Disabilities

NH Public Mental Health Consumer Survey Project

Obesity and Disability Project: Adapting Community-Based Obesity Reducing National Strategies Project





### **S**TAFF

#### **IOD LEADERSHIP**

Charles E. Drum, Director & Professor

Susan Fox, Associate Director

Jennifer Donahue, Director of Finance

Matthew Gianino, Director of Communications

Andrew Houtenville, Director of Research

Mary Schuh, Director of Development & Consumer Affairs

#### FACULTY & STAFF

Derek Ahl, Education Program Coordinator I

MaryAnn Allsop, Senior Program Support Assistant

Peter Antal, Research Associate

Joan Beasley, Director of START Services

Linda Bimbo, Director of Program Operations, Center for START Services

Debra Brucker, Project Director

Sarah Buckovitch, Office Support

Kären Clausen, Senior Program Support Assistant

Heidi Cloutier, RENEW Trainer & Project Coordinator

Brittney DeVincenzo, Office Assistant



Ann Dillon, Program & Clinical Placement

Beth Dixon, Program Coordinator

Sonke Dornblut, Clinical Assistant Professor

Jonathan Drake, Project Training Coordinator

Casey Eyring, Information Technology Specialist

Kathryn Filanoski, Receptionist & **Bookstore Coordinator** 

Kathryn Francoeur, Research Associate

Amy Frechette, ASD Consultant

Arthur Frick, Web Designer

Deb Genthner, Project Coordinator

Penny Gould, Program Support Assistant

Nichole Guntz, Communications & Marketing Assistant

Dan Habib, Filmmaker in Residence

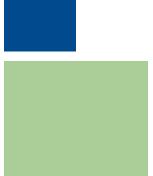
David Hagner, Research Professor

Anne Hurley, Research Associate Professor

Elizabeth Humphreys, NH LEND Training Director

Cat Jones, Events Coordinator





### **S**TAFF

Diann Kashulines, Billing Assistant

Eric Lauer, Project Research Specialist

Anne Long, Outreach & Communications Coordinator, AT Projects

Joanne Malloy, Clinical Assistant Professor

Melissa Mandrell, Project Director

Monica McClain, Research Associate Professor

Michael McSheehan, Clinical Assistant Professor

Julie Moser, Program Manager

Sarah O'Rourke, Senior Program Support Assistant

Susan Orr, Senior Project Support Assistant

Tobey Partch-Davies, Project Director

Kimberly Phillips, Project Director

Kathleen Pirie, Office Manager

Jennifer Rabalais, Project Director

Sarah Rainer, Project Assistant

Leigh Rohde, Clinical Assistant Professor

Jaime Roscoe, Project Development Assistant

Robert Scholz, Project Coordinator

Frank Sgambati, Project Coordinator

Julie Smith, Clinic & Family Coordinator

Karen Smith, Program Coordinator

Rae Sonnemeier, Clinical Associate Professor

Jennifer Squires, Executive Assistant to the Director

Mary Straight, Office Manager

Michelle Stransky, Postdoctoral Research Associate Vidyalakshmi Sundar, Project Director

Maureen Tracey, Education Program Coordinator I

Scott Trudo, Project Director

Jill Varney, Administrative Program Specialist

Shannon Wedge, Online Events & Website Coordinator, START

Therese Willkomm, Clinical Assistant Professor

Michelle Winchester, Health Policy Analyst

\* In addition to the 65 staff represented in this list, the IOD employed 42 additional part-time and adjunct staff in FY 2013 to support its 91 programs, grants, and contracts.

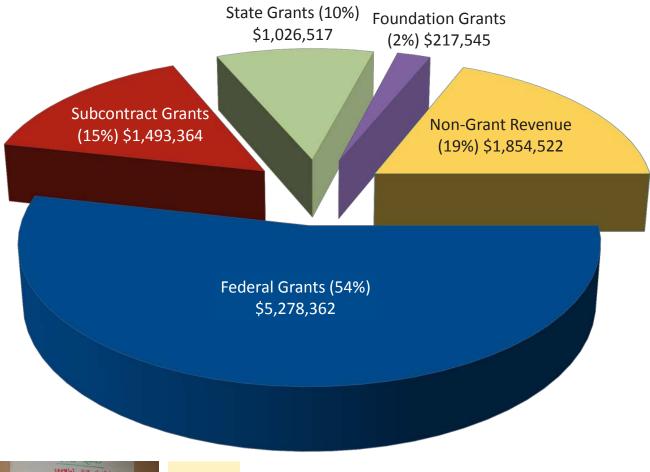


University of New Hampshire

# **FINANCIALS**

The IOD receives core funding from the Administration on Developmental Disabilities (ADD) and obtains funding for other programs and projects through federal grants, state contracts, and private agencies. Despite increased competition over limited resources, the IOD was able to grow its operating budget in FY '13 to the largest in its 26 year history.

IOD FUNDING SOURCES 2012-2013 TOTAL BUDGET: \$9,870,311





### **ADVISORS**

# CONSUMER ADVISORY COUNCIL (CAC)

People with disabilities and their families are central to how the IOD plans, carries out, and evaluates its activities. The CAC is a primary way the IOD involves consumers to guide its activities and priorities.

Steve Alexander – Hudson, NH Gina Colantuoni - Bow, NH Jeff Dickenson – Concord, NH Jackie Driscoll – Derry, NH Bonnie Dunham - Concord, NF Nathan Gams – Hampton, NH Sandy Hicks - Manchester, NH Elizabeth Hillsgrove – Dover, NH Amy Howe – Hopkinton, NH Cabrinni Kulish – Loudon, NH Kirsten Murphy – Hanover, NH Chrissy Shaffer – Litchfield, NH Julie Smith – Durham, NH Jim Tobin – Effingham, NH Patricia Vincent-Piet - Manchester, NH Linda Wadensten – Newport, NH Kathryn Wallenstein – Concord, NH Marian West - Concord, NH

#### **EXECUTIVE COMMITTEE**

The Executive Committee is collectively made up of leaders across several non profit, government, and academic institutions in New Hampshire with an emphasis on disability, education, health, and social services. The Committee meets at least twice per year to review progress toward joint initiatives and identify organizational priorities.

Richard Cohen, Executive Director, Disabilities Rights Center

Charles Drum, Director, Institute on Disability

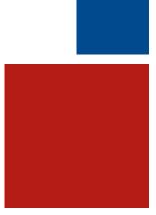
Matthew Ertas, Director, New Hampshire Bureau of Developmental Services

Michael Ferrara, Dean, College of Health & Human Services, University of New Hampshire

Susan Fox, Associate Director, Institute on Disability

Carol Stamatakis, Executive Director, New Hampshire Council on Developmental Disabilities

Santina Thibedeau, Administrator, Bureau of Special Education





#### **OFFICE LOCATIONS**

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Fax: 603.862.3270

Professional Development Center

56 Old Suncook Road

Concord, NH 03301

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Fax: 603.228.3270

Email: events.iod@unh.edu

The IOD Bookstore

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Durham, NH 03824

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Toll Free: 800.378.0386

Fax: 603.862.0555

Email: <a href="mailto:contact@iodbookstore.org">contact@iodbookstore.org</a>

Website: www.iodbookstore.org









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