The Institute on Disability/UCED (IOD) 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.

Cover Image Caption: Makayla (11) and her sister Ariana (9). Makayla is featured on Genetics Education Materials for School Success website as a child with Smith Magenis Syndrome.

Inside Cover Image Caption: Members of the 2017 NH Senior Leadership Series speak with each other and CACL staff member Jennifer Rabalais during their Graduation session.

Back Cover Photo: Thompson Hall at the University of New Hampshire.

This document is available in alternative formats upon request

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The 2016 IOD Annual Report contains data from the FY 2016 Report on Scholarly Activity and Engagement which can be downloaded from the IOD website at: iod.unh.edu
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Photos of Dr. Betsy Humphreys, NH-ME LEND Director, and student.
Dear Friends and Colleagues,

I am happy to present to you the Fiscal Year 2016 Annual Report for the Institute on Disability (IOD) at the University of New Hampshire. We are particularly proud of all we were able to accomplish this past year and hope this report paints a comprehensive picture of our work and impact in an accessible and user-friendly format.

As we begin our 30th year and reflect on our past work, we are reminded that our environment and the needs of individuals with disabilities continuously evolve. In addition to our resolve to stay well-connected to communities in NH and beyond to identify innovative and impactful ways we can support effective change through collaboration, we recognize that creativity and nimbleness will be hallmarks of our future success. We look forward to advancing our capacity in these areas and strategically addressing emerging priorities in the disability community through nurturing existing relationships and forging new partnerships.

Thank you for taking the time to review this report. I welcome any comments and feedback you have about the work of the IOD and appreciate your ongoing support and partnership.

Sincerely,

Charles Drum, MPA, JD, Ph.D.
Director, Institute on Disability, University of New Hampshire
Professor of Health Management and Policy

To view this annual report online, visit our interactive website iodannualreport.unh.edu
Déodonné Bhattarai spends most of her days with her two-and-a-half-year-old son, Bodhi. He’s bilingual, speaks English and Nepali, loves to play with his friends, goes ice skating, and can maneuver his wheelchair almost entirely independently. A year and a half ago, he was diagnosed with Spinal Muscular Atrophy (SMA). Déodonné made the choice to leave her job as a Health Policy Analyst to better manage his care.

A few months after his diagnosis, the IOD’s Mary Schuh and Ann Dillon reached out to Déodonné to set up a meeting. They discussed her needs, and Déodonné joined the NH Leadership Series. While in the series, she joined the New England Genetics Collaborative (NEGC) Genetic Education Materials for School Success (GEMSS) action group. She and six other Series participants did a full review of the existing website, added new content including information about SMA, and worked on dissemination strategies. They presented their findings at the NEGC’s Annual Meeting.

Bodhi hasn’t entered school yet, but the GEMSS site has helped Déodonné prepare. When he begins, a user-friendly website will serve as a resource for his education team. It will provide information about medical equipment, accommodations, and best practices, to ensuring that Bodhi and other students will be fully included in their classrooms. It will share individual stories of students with specific genetic conditions who are happy and thriving. The features on the GEMSS site,“help to change the perception of what expectations you can have for a child with a genetic condition,” shares Déodonné. “They set the expectations high while providing the tools to help achieve them.”

Déodonné currently serves as a member of the IOD’s Consumer Advisory Council and is the Policy Co-Chair of the NH Council on Developmental Disabilities. She also volunteers at the Disability Rights Center in Concord, NH.

“The IOD gave me a lifeline when I needed one, and my continued involvement with the IOD is a way to give back,” explains Déodonné.
EMPOWERING YOUTH TO REACH THEIR FULL POTENTIAL

Jonathon Drake first started working at the IOD as an Undergraduate work-study student more than 15 years ago. He stayed connected to the IOD while he got his Masters in Social Work at UNH. He is also a graduate of the IOD’s LEND Program.

Jonathon was introduced to person-centered planning while in the LEND Program, and the rest, as they say, is history. After graduation, Jonathon began working on what is now the RENEW project. RENEW works with schools to support youth with emotional and behavioral challenges. Jonathon provides support to youth and their RENEW coaches.

When youth take advantage of their resources, surroundings, and apply it to their life wants, needs and goals, they are often able to make tremendous strides,” shares Jonathon Drake. “Experiencing this process with them is unique, invigorating, and inspiring to me.

As a central figure with the RENEW project, Jonathon works to transform the lives of youth across New Hampshire. He provides coaching and technical assistance to New Hampshire high schools and mental health centers implementing RENEW.

He’s also working to translate New Hampshire’s RENEW work and activity to a national audience. One of the key trainers for the RENEW project, he provides support to the US. Department of Education-funded evaluation of the RENEW project – developing fidelity measures and monitoring adherence to them. RENEW currently operates in 12 states and Denmark.

In the coming years, Jonathon will continue to bring his work with youth to a state and national audience as well as finish his Education Specialist Degree in Educational Administration and Supervision from the University of New Hampshire.

*Represents an all-time high

To learn more about RENEW, visit www.renew.unh.edu
A student from ConVal High School’s Next Steps NH program interns in a Middle School physical education class.
HIGHLIGHTS FROM THE PAST YEAR

**JULY 2015**

**Luke Kalb**, a Ph.D. student from Johns Hopkins University’s Bloomberg School of Public Health, received the National Institute of Health’s Ruth L. Kirschstein National Research Service Award Individual Predoctoral Fellowship to measure the impact of Center for START Services’ crisis prevention and intervention services on the lives of people with intellectual and developmental disabilities and behavioral health needs.

**AUGUST 2015**

The IOD hosts Camp CreATe & the Conference on School Culture, Climate, and Positive Behavior Support attracting 296 individuals from around the world.

**SEPTEMBER 2015**

The New England Genetics Collaborative begins a first-of-its-kind partnership with the Genetic Metabolic Center for Education to create a telehealth platform able to support the diagnosis and treatment of inherited metabolic disorders throughout New England.

**OCTOBER 2015**

**Dr. Debra Brucker** receives a three-year, $100,000 cooperative agreement from the USDA’s Economic Research Service to look at how food security might influence economic and health outcomes for persons with disabilities.

**NOVEMBER 2015**

IOD receives 5-year, $4.3 million grant from NIDILRR for the Employment Policy & Measurement Rehabilitation Research & Training Center to improve knowledge about and access to existing disability data, and generating the knowledge needed to improve future disability data collection and dissemination.

**DECEMBER 2015**

**Dr. Karla Armenti** and the New Hampshire Occupational Health Surveillance Program join the IOD from the NH Division of Public Health Services. Funded by the CDC, the project provides meaningful statistics to identify priority occupational safety and health issues in the state.

Dr. JoAnne Malloy gives keynote “Linking School Behavioral Health Within a Multi-tiered System of Support” at Bradley F. Kidder Educational Law Conference in Concord, NH.
JANUARY 2016

More than a dozen IOD staff members braved an unexpected snowstorm to present their recent projects and findings at the biennial UNH College of Health & Human Services Research Conference.

MARCH 2016

The monthly nTIDE Lunch & Learn Webinar Series launches to discuss the latest national news and statistics in disability employment.

MAY 2016

The NH Children’s Behavioral Health Workforce Development Network issues a report, Improving Child & Community Health: Addressing Workforce Challenges in Our Community Mental Health Centers, which examines the characteristics of the children’s mental health workforce, the impact of staff turnover, and the perspectives of the workforce on successful strategies.

FEBRUARY 2016

The IOD launches From Where I Sit, a new blog written by Kathy Bates providing a first-person voice on various trending disability-related topics.

APRIL 2016

Dr. Sue Fox, IOD Associate Director, receives commendation from NH Governor Maggie Hassan for her leadership as co-director of the UNH Center on Aging and Community Living and as a founding member of the Governor’s Commission on Medicaid Care Management.

JUNE 2016

NH LEND trainees from NH and Maine traveled to Washington, DC, to participate in the Disability Policy Seminar where they received intensive advocacy training and met with their elected officials and staff on Capitol Hill to advocate for the Reauthorization of the Lifespan Respite Care Reauthorization Act.

The NH Disability & Public Health Project releases its 2016 report on social determinants of health, access to health care, and health indicators.

Dr. Betsy Humphreys co-presents a session on Identifying Leadership Frameworks for Early Intervention at the International Society on Early Intervention Conference in Stockholm, Sweden.
Students from YouthMOVE NH participate in the youth strand at the 2015 Conference on School Culture, Climate, and Positive Behavior Supports.
Mark Joyce is retired from the Air National Guard and the federal government. He has lived with an “essential tremor” for a long time, but in the past few years, the tremor worsened, to the point where he’s begun having difficulties with daily activities like eating, brushing his teeth, making phone calls, and typing on his phone. After hearing a presentation by staff at Assistive Technology in New Hampshire (ATinNH), a friend suggested that Mark give the program a call. Mark reached out to Stacy Driscoll and made an appointment to discuss his needs and test out potential assistive technology solutions. Over the course of three visits, Stacy and Dr. Therese Willkomm tested out dozens of potential adaptations and solutions to make Mark’s life easier. One of the technologies is showing him ways to use features of his iPhone that make communication quick and easy.

“When I pick up my phone, and I have to text someone, it is a long, arduous process for me,” shares Mark. After getting set up and trained with voice-to-text technology, things got easier. “To be able to pick it up and talk in it. My anxiety is a lot less. I know I’ll be successful in getting my message sent.”

Stacy and Therese also manufactured a number of solutions for Mark including a lap board for resting his work and a moldable plastic grip to adapt his stylus.

“One of the best things about Stacy and Therese is that they have no boundaries in terms of what they’re willing to do and try in a given situation,” shares Mark. “I never hear them say, ‘oh no, we can’t do that.’ They’d try anything until they found a solution that worked for me.”
**SERVICE**

**COMMUNITY SERVICE ACTIVITIES**

87*  
LOCAL, STATE, & NATIONAL COMMITTEES & BOARDS

56*  
MEMBERSHIPS IN PROFESSIONAL ASSOCIATIONS

28*  
UNIVERSITY COMMITTEES & COMMISSIONS

25*  
EDITORIAL & REVIEW ACTIVITIES

6*  
GRANTING AGENCY REVIEW ACTIVITIES

**TECHNICAL ASSISTANCE**

9,477  
HOURS PROVIDED

1,520  
INDIVIDUALS SERVED

**PUBLIC EVENTS**

35  
IOD TRAININGS, WORKSHOPS, WEBINARS & CONFERENCES

3,229  
PARTICIPANTS

3.52*  
AVERAGE SATISFACTION RATING (SCALE FROM 0-4)

*Represents an all-time high

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**BUILDING A STATEWIDE ADVOCACY NETWORK**

Jennifer Rabalais has been working since 2010 as an IOD Project Director to increase the capacity of NH’s communities and organizations meeting the needs of older adults and individuals with disabilities in community-based settings. Working primarily with the Center on Aging & Community Living (CACL), her work has focused on projects that strengthen the pool of quality direct care workers, balance the use of long-term services and supports between institutions and communities, and advance healthy aging in NH. Jennifer also provides support and training in advocacy and leadership skills to advance issues of importance for New Hampshire citizens as they age.

One of her major priorities this past year was the NH Alliance for Healthy Aging, a statewide coalition of cross-sector stakeholders focused on the health and well-being of elders in New Hampshire. The Alliance’s vision is to create communities in New Hampshire that advance culture, policies, and services supporting older adults and their families. One of the established priorities of the group is building an advocacy infrastructure to support aging issues in NH. The group is currently convening advocates from across the state and working towards establishing long-term policy priorities for aging in NH.

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The aging population is the fastest growing population in NH right now,” explains Jennifer. “It is imperative that we not only plan thoughtfully to prepare for the needs of this growing population but also consider how to best utilize the unique resources and skills of this group.”

In the coming year, Jennifer will be participating in the Leadership Learning Exchange for Equity, a program for leaders across the state to reflect, learn, and act to address racial bias. Jennifer looks forward to sharing the lessons learned from this training, as well as the many experiences from her work, with a broader regional audience.

To learn more about the Center for Aging & Community Living, visit www.agingandcommunityliving.org.
$11,066,825*

TOTAL BUDGET

102*

GRANTS AND CONTRACTS

*Represents an all-time high

Dr. Andrew Houtenville presents at the release of the Annual Disability Statistics Compendium in Washington, D.C.
FACULTY, STAFF, & LEADERSHIP

MANAGEMENT TEAM

Charles E. Drum  
Director & Professor

Susan Fox  
Associate Director

Jennifer Donahue  
Finance Manager

Matthew Gianino  
Director of Communications

Andrew Houtenville  
Director of Research

Mary Schuh  
Director of Development & Consumer Affairs

EXECUTIVE COMMITTEE

Charles Drum  
Director & Professor

Susan Fox  
Associate Director

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

Amy Messer  
Executive Director, Disability Rights Center

Clyde Terry  
Chief Executive Officer, Disability Rights Center

Lorene Reagan  
Bureau Chief, New Hampshire Department of Health & Human Services, Bureau of Developmental Services

Santina Thibedeau  
State Director of Special Education, Bureau of Special Education

John Richards  
Interim Director, New Hampshire Council on Developmental Disabilities

*Represents an all-time high
CONSUMER ADVISORY COUNCIL
& OFFICE LOCATIONS

CONSUMER ADVISORY COUNCIL (CAC)

Steve Alexander
Deodonne Bhattarai
Lisa D. Beaudoin
Jennifer Bertrand
Ellen Boudreau
Gina Colantuoni
Jeff Dickinson
Jackie Driscoll
Penny Duffy
Bonnie Dunham

Nathan Gams
Amy Girard
Sandy Hicks
Richard Johnson
Cabrinni Kulish
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Jim Tobin
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Website: www.iodbookstore.org

Dan Habib filming a subject for an upcoming documentary film.
STAY CONNECTED WITH THE IOD