INSTITUTE ON DISABILITY / UCED

2016 ANNUAL REPORT

July 1, 2015 – June 30, 2016







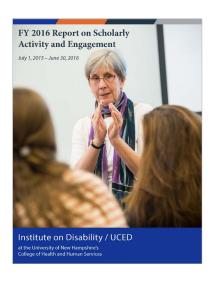
Cover Image Caption: Makayla (11) and her sister Ariana (9). Makayla is featured on Genetics Education Materials for School Success website as a child with Smith Magenis Syndrome.

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

© February 2017. Institute on Disability. University of New Hampshire 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.



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

Charles Drum, MPA, JD, Ph.D.

Director, Institute on Disability, University of New Hampshire Professor of Health Management and Policy



RESEARCH & PUBLICATIONS



14
PEER-REVIEWED
ARTICLES



BOOKS AND BOOK CHAPTERS

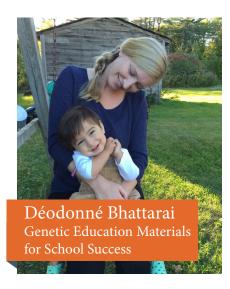


4
TRAINING CURRICULA



33
OTHER DISSEMINATION
MATERIALS

BUILDING A FOUNDATION FOR SCHOOL SUCCESS



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.



To learn more about Genetics Education Materials for School Success, visit www.gemssforschools.org.



TEACHING

18
UNH COURSES



19*
GUEST LECTURES



278
NUMBER OF
STUDENTS

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





HIGHLIGHTS FROM THE PAST YEAR



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.



JULY 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.



Dr. Debra Brucker receives a threeyear, \$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.

SEPTEMBER 2015



The IOD celebrates the **25th Anniversary of the ADA** at UNH with the on-campus Equality & Access Fair as well as Spencer West speaking as a part of the Krumm Lecture Series.

NOVEMBER 2015

AUGUST 2015



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

OCTOBER 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.



Dr. JoAnne Malloy gives keynote "Linking School Behavioral Health Within a Multitiered System of Support" at

Bradley F. Kidder Educational Law Conference in Concord, NH.

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.

Occupational Health Surveillance Program





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.



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



Tobey Partch-Davies named Co-Chair of the UNH President's Commission on the Status of People with Disabilities.

MARCH 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.

MAY 2016

JANUARY 2016

FEBRUARY 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.



Dr. Sue Fox,
IOD Associate
Director, receives
commendation
from NH Governor
Maggie Hassan for
her leadership as

APRIL 2016

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.



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.

JUNE 2016



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 copresents a session on Identifying Leadership Frameworks for

Early Intervention at the International Society on Early Intervention Conference in Stockholm, Sweden.



DISSEMINATION

PEER-REVIEWED AND **INVITED PRESENTATIONS:**



INTERNATIONAL



133 **NATIONAL**



STATE AND LOCAL

OUTREACH & ENGAGEMENT



26,156 EMAIL SUBSCRIBERS MASS EMAILS



BOOKSTORE ORDERS

BOOKSTORE

SATISFACTION RATE



34

PRESS RELEASES

15

MENTIONS IN THE MEDIA



75,078* WEBSITE VISITS **57,066*** WEBSITE VISITORS

3,236 WEBSITE DOWNLOADS

SOCIAL MEDIA



2,223* 1.055*

TWITTER FOLLOWERS

TWEETS



2,886* **812***

FACEBOOK FOLLOWERS

POSTS

693[†]

IOD BLOG POSTS

VISITS

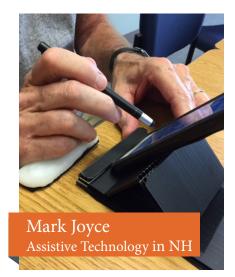
61*

YOUTUBE VIDEOS

11,019 VIEWS

28,807 MINUTES WATCHED

SIMPLE SOLUTIONS TO LIVING LIFE EVERYDAY



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

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."

^{*}Represents an all-time high † Represents first year of activity



To learn more about the Assistive Technology in New Hampshire project, visit www.atinnh.org.



SERVICE

COMMUNITY SERVICE ACTIVITIES

87*

LOCAL, STATE, & NATIONAL COMMITTEES & BOARDS

56*

MEMBERSHIPS IN PROFESSIONAL ASSOCIATIONS

28*



25*

EDITORIAL & REVIEW ACTIVITIES

6*

GRANTING AGENCY REVIEW ACTIVITIES

TECHNICAL ASSISTANCE



9,477 HOURS PROVIDED



1,520 INDIVIDUALS SERVED

PUBLIC EVENTS



OD TRAININGS, WORKSHOPS, WEBINARS & CONFERENCES



3,229PARTICIPANTS



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

*Represents an all-time high

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 communitybased 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.

fastest growing 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.



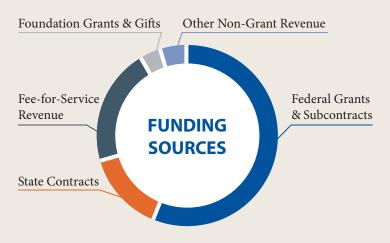
To learn more about the Center for Aging & Community Living, visit www.agingandcommunityliving.org.



FINANCIALS, GRANTS, & CONTRACTS

\$11,066,825*

TOTAL BUDGET





102*

GRANTS AND CONTRACTS

Federal Grants



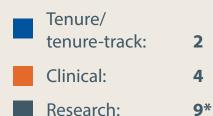
Consulting Agreements:

^{*}Represents an all-time high



39







Full-time: 56

Part-time: 29

FACULTY, STAFF, & LEADERSHIP

MANAGEMENT TEAM



Charles E. Drum Director & Professor



Susan Fox
Associate Director



Jennifer Donahue *Finance Manager*



Matthew Gianino
Director of
Communications



Andrew HoutenvilleDirector 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
Chrissy Shaffer
Jim Tobin
Linda Wadensten
Kathryn Wallenstein

OFFICE LOCATIONS

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Email: contact.iod@unh.edu

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