

INSTITUTE ON DISABILITY / UCED

# 2019

# ANNUAL REPORT



**Institute on Disability / UCED  
At the University of New Hampshire  
College of Health and Human Services**

**July 1, 2018 – June 30, 2019**



*Inside Cover Image Caption: IOD Web Services Coordinator Kate Filanoski receiving an award at an IOD staff meeting.*

*Cover Image Caption: NH Leadership Series Coordinator Deb Genthner smiling at an IOD staff meeting.*

## ABOUT THE INSTITUTE

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.

Institute on Disability/UCED



[iod.unh.edu](http://iod.unh.edu)



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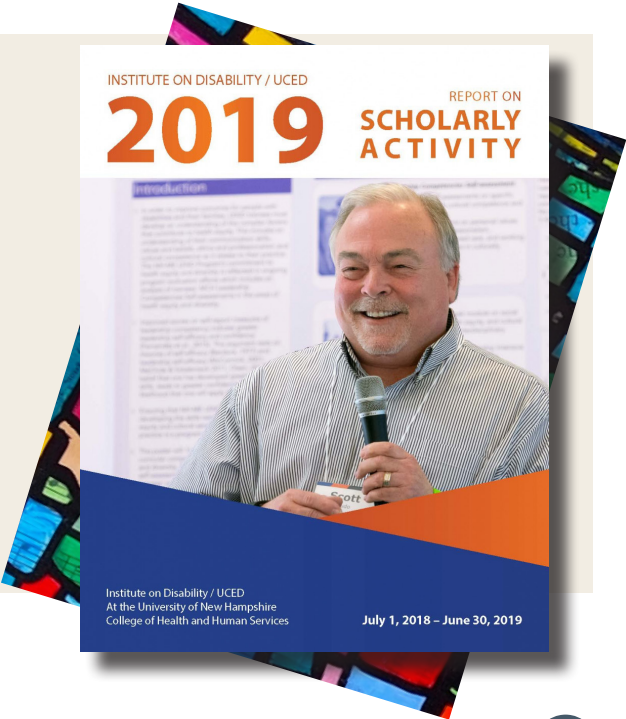
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## 2019 ANNUAL REPORT

The 2019 IOD Annual Report contains data from the FY 2019 Report on Scholarly Activity and Engagement, which can be downloaded from the IOD website at [iod.unh.edu](http://iod.unh.edu).

 To view this annual report online, visit our interactive website [iodannualreport.unh.edu](http://iodannualreport.unh.edu).

This document is available in alternative formats upon request.





Over the last year, the IOD has remained steadfast in its 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. We at the IOD, along with our community, have experienced both subtle and dramatic changes in how we approach our mission. Changes due to COVID-19, social distancing, online learning, community unrest, and civil rights injustices have demanded that we find new and more inclusive ways of approaching our work and commitment to service, research, and training. Now more than ever, the IOD's values call on us to be responsive, flexible, and open to the new challenges and asks of our work. The disability community is no stranger to the face of injustice, and we have worked for more than a generation on increasing participation, inclusion, and belonging of all people. We are committed to the hard work of listening, caring, respecting, engaging, and healing with our communities.

The IOD has remained strong and nimble under the leadership of Andrew Houtenville and Linda Bimbo, who served as Acting Director over the last three years. Their leadership allowed the IOD to focus on things it values most—choice, self-directed supports, community inclusion, and cultural and linguistically competence across the life span. Both Andrew and Linda used their extensive experience within the IOD to support the organization through a time of transition. On the other side of that transition, as the new Director as of June 2020, I am committed to leading the IOD into its next season of growth, innovation, and service. I am inspired and motivated by the work I have witnessed at the IOD. In the coming years, I look forward to meeting and learning from individuals, families, partners, and collaborators across the state.

We will be most successful in the future when we partner with our community as we rise to meet the opportunities and challenges that lie ahead. In the year ahead, the IOD will remain a strong voice, partner, ally, and leader as we work to advance the inclusion and belonging of individuals living with disability and their families. Thank you for your partnership. We welcome more opportunities for learning and growing with you.

Sincerely,

Kelly Nye-Lengerman, Ph.D.

Director Institute on Disability, University of New Hampshire

# IOD'S AREAS OF EMPHASIS (AoE)

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 the institute's grants and programs are concentrated within four strategic Areas of Emphasis (AoE): Community Living & Employment; Health

& Genetics; Assistive Technology; Inclusive Early Care & Education. By design, this report paints a comprehensive picture of each AoE and the tangible impact the projects and grants have had on individuals with disabilities.

## PERCENTAGE OF PROJECTS & GRANTS BY AoE



<div></div>	INCLUSIVE EARLY CARE & EDUCATION	36%
<div></div>	ASSISTIVE TECHNOLOGY	13%
<div></div>	COMMUNITY LIVING & EMPLOYMENT	34%
<div></div>	HEALTH & GENETICS	26%

## COMING SOON!

The IOD announced Behavioral Health & Wellness will be added as a fifth area of emphasis in FY20. The initiative will expand the institutes's strong collection of resources, expertise, and services dedicated to supporting individual, social, and emotional wellness in schools and communities.

*To learn more about the IOD's new AoE visit [iod.unh.edu/behavioral-health-wellness](http://iod.unh.edu/behavioral-health-wellness).*



# IMPROVING OUTCOMES FOR CHILDREN

As a behavior specialist, Stacy Champey consults on special education cases involving students with emotional and behavioral challenges (EBC). With the right supports, Stacy believes any student can succeed in school. Yet many schools lack proper personnel or supports that children and youth with significant needs, including those with EBC, developmental and intellectual disabilities, autism, sensory, and other learning disabilities, to be successful. Even with the right resources, change in no way comes easily, especially in large districts like Manchester, New Hampshire.

“It’s hard to bring change in a big district,” says Stacy. “You just kind of chug along, year to year to year to year... doing things the same way.” Through her position with the school district, she was connected with Dr. JoAnne Malloy, a Research Associate Professor at the Institute on Disability at the University

of New Hampshire, who encouraged her to apply for her Trauma Informed Policy and Practice graduate program (TIPP). “It sounded like it was a natural fit for me and really dovetailed the work that I’m currently doing at Manchester as a behavior specialist... So I applied for the program.”

TIPP prepares graduate social work and special education scholars in research-based practices and systems change strategies to improve outcomes for children and youth with significant support needs. The program, co-taught by Dr. JoAnne Malloy and Dr. Mary Schuh, is unique as it brings together special educators and social workers to learn about the adverse impacts of trauma and building resiliency and inclusion at the individual, family, school, and community levels.

“The TIPP program helped me to look closer at special education and some of the practices that we have in



*Image Caption: Stacy Champey*

our district.” Stacy believes the program challenged her thinking and philosophical approach to education. “It was a great experience to connect with other special educators and social workers in this course. We realized we have a common vision and a common mission.”

For those considering the program, Stacy advises keeping an open mind, “Some people are going to go in and think this course is about a solution or strategies for working with students that have experienced trauma. This is definitely built into the course, but it is so much more than that.”





*“The TIPP program helped me to look closer at special education”*

## INCLUSIVE EARLY CARE & EDUCATION

We believe that the benefits of equity-based inclusive education may be realized for each and every learner, in each and every neighborhood. IOD’s work in Inclusive Early Care and Education is nationally recognized for cutting edge research, teaching, and service related to children and youth.

## FOCUS AREAS

Our work in this field is focused on improving services and outcomes for students with disabilities. Focus areas include:

- Early Childhood, Elementary, Middle and High School, Post-Secondary Education
- Dropout Prevention
- Transition from School to Adult Life
- Youth Empowerment and Leadership
- Promoting Family and School Partnerships
- Response to Instruction and Intervention
- Positive Behavioral Interventions and Supports /Positive Behavior Supports

- Augmentative and Alternative Communication
- Alternate Assessment
- Public Awareness and National Media
- School, District, and State-level Systems Change
- Response to Instruction and Intervention

## PROJECTS & GRANTS

- Center on Inclusive Education (CIE)
- Including Samuel
- Inclusive Communities
- Mr. Connolly Has ALS
- Multi-tiered System of Support (MTSS)
- New Hampshire-Maine Leadership Education in Neurodevelopmental Disabilities Program (LEND)
- Resilience, Empowerment, and Natural Supports for Education and Work (RENEW)
- UNH TIPP
- UNH-4U
- Who Cares About Kelsey?

*To learn more about the IOD’s commitment to Inclusive Early Care & Education visit [iod.unh.edu/inclusive-early-care-education](http://iod.unh.edu/inclusive-early-care-education).*

# LOW-COST, HIGH-VALUE

Nate Loomis was 18 when a bodysurfing injury paralyzed him from the chest down and impaired his fine motor skills in his hands and arms. As a freshman at UNH, he dreamed of going to the Rhode Island School of Design, “I actually found out that I got accepted while I was in rehab,” says Nate. “When you’re working on an artwork, it’s like, it’s like a part of your heart and soul goes into it. So when it’s not coming out the way you want, it can be frustrating and emotional.”

By coincidence, years later Nate took a job in the same building as UNH’s OT department, where Dr. Therese Willkomm works. Dr. Willkomm is the Director of ATinNH and is well known as “The MacGyver of Assistive Technology,” because of her low-cost high-value rehabilitation technology solutions. Out of curiosity, Nate dropped by her office when the tip of his typing stick fell off, “They went into



*Image Caption: Nate Loomis*

their closet, sort of like a craft closet, where they have every little doohickey in the world... and in about 30 seconds I was on my way back to work.”

A lot of times we look at the adaptive equipment as utilitarian. Whether it’s kitchen utensils or electronics, or costly equipment, like screen readers, or prosthetics, “Oftentimes these things are so expensive and later you come to find out they’re not made very well... So this perspective of being able to


like source everyday materials and inexpensive materials or recycled materials like to me, is one of the coolest things.

It didn’t take long for Nate to return to ATinNH, this time with a personal request—to help him create art again. “They tackled my desire to create art as intently as they would any other problem and, with a ton of enthusiasm and encouragement.” Through the AT4ALL equipment database, Dr. Willkomm outfitted Nate with an iPad Pro and Apple Pencil, “I just started sketching and it felt like I had a lot of my old ability back,” shares Nate.



Assistive Technology in New Hampshire  
[ATinNH.org](http://ATinNH.org)





*“They gave me this huge part of  
my life back.”*

“It was a really emotional experience. It was like they gave me this huge part of my life back.”

“People really need to know that this is there for them in the community,” says Nate. “They have a true passion for their field and it just comes across every time I interact with them.”

Currently, Nate works at Northeast Passage as Annual Fund & Donor Communication Coordinator where he manages development and marketing communications. He continues to stay in touch with ATinNH and helps test student-designed prototypes.

## ASSISTIVE TECHNOLOGY

The IOD is actively involved in partnerships on campus, throughout the state, and on a national level to promote access to assistive technology services. Assistive technology (AT) is integral to the daily lives of many New Hampshire residents. Awareness of and the ability to try AT devices are important aspects to making a decision whether a particular technology is “the right fit.”


## FOCUS AREAS

Assistive Technology at the IOD is focused on three primary goals:

- Expanding access to demonstrations and loans of AT
- Increasing reuse of AT equipment
- Providing excellent training and educational opportunities

## PROJECTS & GRANTS

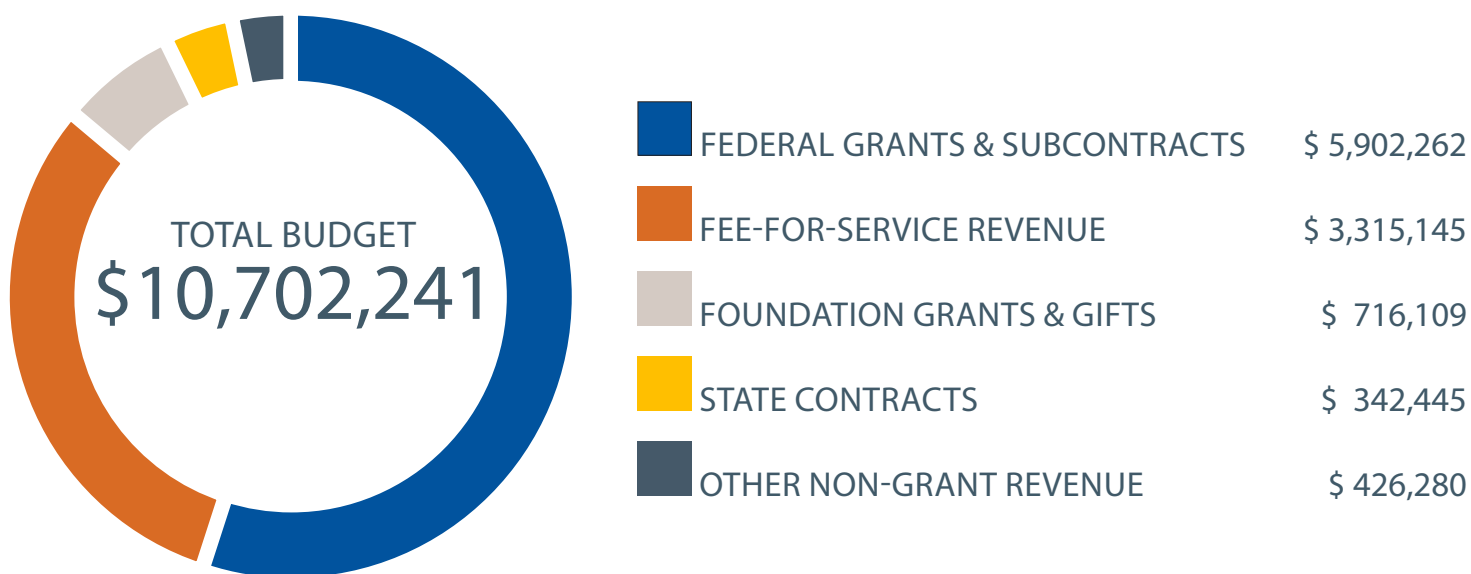
- Assistive Technology in New Hampshire
- NH AT4ALL
- Accessibility Webinar Series
- AT Makers Fair
- Camp CreATe
- UNH Assistive Technology Certificate



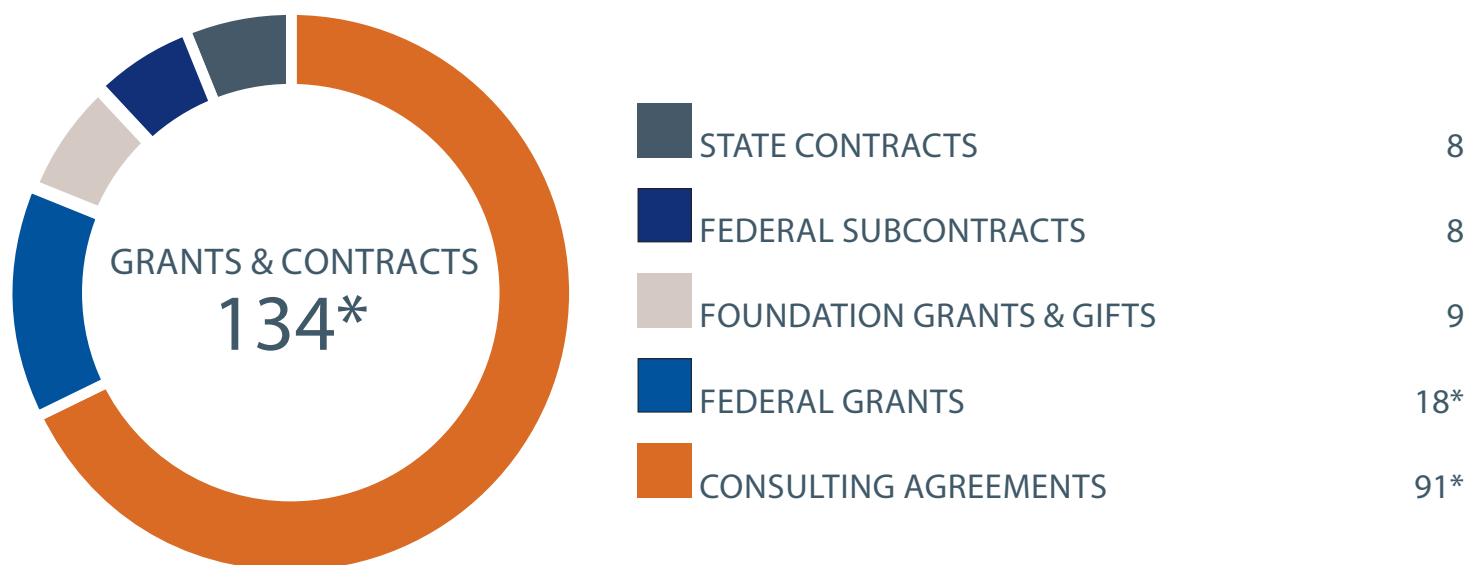
*To learn more about the IOD’s commitment to Assistive Technology and how to make you’re own ATinNH marker grip, visit [iod.unh.edu/assistive-technology](http://iod.unh.edu/assistive-technology).*

# FINANCIALS, GRANTS, & CONTRACTS

## FUNDING SOURCES



## GRANTS & CONTRACTS



*\*Represents an all-time high*

# PUBLICATIONS, ACADEMICS, & COMMUNITY SERVICE

## PUBLICATIONS



22 PEER-REVIEWED  
ARTICLES



5 BOOKS & BOOK  
CHAPTERS



19 OTHER DISSEMINATION  
MATERIALS



4 TRAINING  
CURRICULA

## TEACHING



28\* UNH COURSES  
NUMBER OF STUDENTS: 403\*



17 UNH GUEST  
LECTURES



11 E-LEARNING COURSES  
NUMBER OF STUDENTS: 774\*

## PEER-REVIEWED & INVITED PRESENTATIONS



14\* INTERNATIONAL



112 NATIONAL



42 STATE AND LOCAL

## COMMUNITY SERVICE



48 LOCAL, STATE, & NATIONAL COMMITTEES & BOARDS  
34 MEMBERSHIPS IN PROFESSIONAL ASSOCIATIONS  
19 EDITORIAL AND REVIEW ACTIVITIES  
16 UNIVERSITY COMMITTEES & COMMISSIONS  
4 GRANTING AGENCY REVIEW ACTIVITIES

*\*Represents an all-time high*



# I DON'T NEED TO BE FIXED

The first thing they do at Leadership is give you a microphone and ask you to share your hopes, fears, and gifts.” Kathy has Cerebral Palsy, which can affect the clarity of her speech and mobility. She remembers watching anxiously as the mic made its way around the room. “I was worried about what I was going to say and if I was going to drop the mic,” says Kathy, “and at that time, ‘dropping the mic’ wasn’t a thing.”

Weeks later, Kathy attended a Leadership class led by disability activist Norman Kunc, who also has Cerebral Palsy. “He said it was ok to be disabled, and I didn’t need to be fixed because disability is part of every culture and every segment of society. It might sound ridiculous, but at that moment, it felt as if a big weight was lifted off my shoulders... It was the most



*Image Caption: Kathy Bates facilitating a discussion with students at a NH Leadership Series class.*

important life lesson I could have ever learned.” The class helped her realize that life is full of possibilities, and she deserved to live life to the fullest, just like anyone else. “After that first year, I was like, give me a microphone!”

Since graduating in 1998, Kathy has become a prominent advocate for people with disabilities in the areas of employment, self-directed care, education, and rights. She has been a featured speaker at numerous conferences and workshops around New England.

“A good life is a life of our choosing, and we have more choice if we are involved,” says Kathy. “I still don’t know if people absolutely listen, but communication is my thing, and I have a right to live a good life.”

This summer, Kathy retired from the New Hampshire Leadership Series after serving over 20 years as a group leader and mentor. She will continue to advocate for disability rights through her work at the IOD, writing, volunteerism, and business, Wings and Wheels Consulting Services.





*“It was the most important life lesson  
I could have ever learned.”*

## COMMUNITY LIVING & EMPLOYMENT

The IOD’s Community Living and Employment priority area is a trusted university-based resource for research, evaluation, and technical assistance for the improvement of knowledge, policies, and practices to guide NH citizens and policy makers. Initiatives aim to strengthen communities to assure full access, equal opportunities and full participation for adults with disabilities and those who are aging into and with disabilities.


### FOCUS AREAS

The Community Living and Employment priority area encompasses a broad range of work related to adults; including:

- Transition to adult life
- Employment
- Housing
- Transportation
- Person-centered planning
- Family leadership
- Aging and caregivers

## PROJECTS & GRANTS

- Center for START Services (CSS)
- Center on Aging and Community Living (CACL)
- Job Crafting for People with Physical and Mild Cognitive Disabilities
- Food Insecurity
- US Department of Housing and Urban Development (HUD)
- Inclusive Communities
- Janet Krumm Disability & Media Lecture Series
- Kessler Employment Surveys
- Living Well
- NH RAPP Sheet
- NH Wraparound
- NH Leadership Series
- Rehabilitation Research and Training Center on Disability Statistics and Demographics (StatsRRTC)
- Rehabilitation Research and Training Center on Employment Policy and Measurement (EPM-RRTC)
- UNH-4U



To learn more about the IOD’s commitment to Community Living & Employment visit [iod.unh.edu/community-living-employment](http://iod.unh.edu/community-living-employment).

# DISSEMINATION & SERVICE

## WEBSITE



## SOCIAL MEDIA



108\* VIDEOS  
42,098\* MINUTES  
WATCHED



716 TWEETS



630 POSTS



38\* BLOG POSTS

*\*Represents an all-time high*



## OUTREACH & ENGAGEMENT



41 PRESS RELEASES



20 MENTIONS  
IN THE MEDIA



1,305 BOOKSTORE ORDERS  
97.4% SATISFACTION



34,266 SUBSCRIBERS  
222\* MASS EMAILS

## PUBLIC EVENTS



51 EVENTS  
*Workshops, Webinars,  
& Conferences*



3,746 PARTICIPANTS



3.62 AVERAGE  
SATISFACTION  
*Scale 0-4*

## TECHNICAL ASSISTANCE



6,197\* HOURS  
PROVIDED



5,287 RECIPIENTS

*\*Represents an all-time high*

# A COMMON GOAL

Even though treatment options and genetic resources have gotten better in recent years, the pool of genetic care specialists is small. “There’s not a lot of genetic providers, especially in Rhode Island, and especially for children,” says Tara Hayes. “NERGN is trying to make sure that anybody who needs access to services and support can get it.”

Tara has been an active and engaged member of the health and genetics community for 12 years. A Family Voices Manager at the Rhode Island Parent Information Network (RIPIN) and mother of a child with a rare health disorder, Tara’s uniquely qualified to serve on the New England Regional Health Network’s (NERGN) Advisory Committee. NERGN aims to improve the quality of coordinated and comprehensive genetic services for children and their families in New England. As a member of NERGN’s Advisory



*Image Caption: Tara Hayes speaking at annual caregivers conference.*

Committee, Tara helps identify gaps and opportunities to better support Rhode Island families.


“There are so many different diagnoses and conditions and things that families find out along the way of their life journey that can be really tough.”

Some genetic conditions only affect a small number of people, and a diagnosis doesn’t guarantee there’s a definitive treatment. Finding trusted resources and specialists while managing a child’s health can become a full-time job. Tara

believes NERGN’s collaborative approach has been instrumental in improving family-centered care in her state. “We’re all working together around a common goal,” says Tara. “They’re in it for the family, they’re in it for their patient, and not personal gain.”

In 2018, Tara Hayes was nominated for caregiver of the year for her work with RIPIN and her role in caring for her own son, Andrew, who was born with a rare congenital neuromuscular disorder that medical experts thought would take his life within days of being born. Andrew is now 12 years old and thriving.

**nergn** NEW ENGLAND  
REGIONAL GENETICS  
NETWORK



*“They’re in it for the family, they’re in it for their patients, and not for personal gain.”*

## HEALTH & GENETICS

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

### FOCUS AREAS

IOD staff collaborates with public health officials, families, care-givers, primary and specialty health care providers, and other agencies and individuals on multiple projects within the state of New Hampshire, New England, and nationally. Project goals include:


- Enhance local clinical services, education and training capacity
- Provide technical assistance, accessible information, educational opportunities, and other support for individuals and agencies who support those with genetic disorders
- Increase early screening, diagnosis, and effective family-centered treatment of children with autism
- Prepare health care professionals to assume

leadership positions

- Improve community-based care systems
- Provide family-centered and culturally sensitive interdisciplinary evaluation and consultation
- Transform the older adults service delivery system to caregiver-directed, locally-managed models

### PROJECTS

- Center for START Services (CSS)
- Creating Connections NH
- Health Disparities & Intellectual Disability
- Health Disparities Project
- Maternal Infant and Early Childhood Home Visiting (MIECHV) Evaluation
- New England Regional Genetics Network
- NH Disability & Public Health Project
- NH Children’s Behavioral Health Workforce Development Network
- New Hampshire-Maine Leadership Education in Neurodevelopmental Disabilities Program
- Occupational Health Surveillance Program
- Understanding food-related hardships among older Americans: Evidence from the Panel Study of Income Dynamics Project



*To learn more about the IOD’s commitment to Health & Genetics visit [iod.unh.edu/health-genetics](http://iod.unh.edu/health-genetics).*



# FACULTY, STAFF & LEADERSHIP

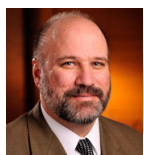
## MANAGEMENT TEAM



Jennifer Donahue  
Finance Manager



Matthew Gianino  
Associate Director



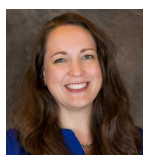
Andrew Houtenville  
Research Director



Betsy Humphreys  
NH-ME LEND  
Program Director



JoAnne Malloy  
RENEW  
Program Director



Kelly Nye-Lengerman  
Director



Luke Reynard  
CSS  
Director of Operations

## EXECUTIVE COMMITTEE

Kelly Nye-Lengerman  
Director, Institute on Disability

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

Stephanie Patrick  
Executive Director, Disability  
Rights Center - New  
Hampshire

Isadora Rodriguez-Legendre  
Executive Director, New  
Hampshire Council on  
Developmental Disabilities

Christine Santaniello  
Director, New Hampshire  
Bureau of Developmental  
Services



<span style="color: orange;">■</span>	FULL TIME	51
<span style="color: gray;">■</span>	PART TIME	28
<span style="color: darkblue;">■</span>	STUDENT EMPLOYEES	4



<span style="color: orange;">■</span>	TENURE TRACK	1
<span style="color: gray;">■</span>	CLINICAL	2
<span style="color: darkblue;">■</span>	RESEARCH	6

5



HONORS, AWARDS  
& FELLOWSHIPS

# CONSUMER ADVISORY COUNCIL

People with disabilities and their families are central to how the Institute on Disability plans, carries out, and evaluates its activities. The Consumer Advisory Council (CAC) is one of the primary ways the IOD engages individuals,

families, and partners to inform the work of the Institute. CAC members meet four times a year and serve as a connection to our greater community.

## MEMBERS

Lisa D. Beaudoin  
Forrest Beaudoin-Friede  
Jennifer Bertrand  
Deodonne Bhattaral  
Gina Colantuoni  
Bonnie Dunham

Bob English  
Richard Johnson  
Darienue McGuinness  
Stephanie Patrick  
Danielle Poirier  
Jill Prakop

Isadora Rodriguez-Legendre  
Marie Primeau  
Crissy Shaffer  
Jan Skoby  
Kathryn Wallenstein

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Toll Free: 800.378.0386  
Fax: 603.862.0555  
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Website: [www.iodbookstore.org](http://www.iodbookstore.org)



# STAY CONNECTED WITH THE IOD



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