Welcome to the Institute on Disability

2021 Annual Report

July 1, 2020 – June 20, 2021

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Despite the uncertainties and challenges created by the global pandemic, there is much to recognize at the Institute on Disability (IOD) this past year. Some types of work have slowed down as a result of COVID, but other priorities and opportunities have also accelerated. Our Annual Report highlights examples of IOD’s impact across more than 36 projects and programs. There is too much incredible work going on at the IOD to capture it all in one report, but to the right are a few meaningful things worth mentioning.

The IOD is a vehicle for inclusion, and our training, research, and service are designed for the betterment of our community, state, and nation. Our work strives to improve the quality of life of those impacted by disability. As a UCEDD, we understand everything matters, from how an individual is included in community to how a legislator is informed about policy impact. We pursue work based on our relationships and connections to you, our communities, and our state.

I hope you enjoy reading our Annual Report, and that within it, see many things you are passionate about. Our work continues, as there is much more to be done to make inclusion and belonging truly part of all human experiences. We can’t do it all, but we can do more with you.

Sincerely,

Kelly Nye-Lengerman, PhD
Director Institute on Disability at the University of New Hampshire

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About the IOD

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.

The IOD serves as a bridge between the university and the community by:
- Teaching and training others on issues that affect people with disabilities
- Participating in current research, evaluation, and analysis
- Communicating and sharing information with many people
- Providing services and supports to people with disabilities and their families

The IOD is able to do this work by collaborating with others including:
- People with disabilities and their families
- Federal and state agencies
- Service providers and nonprofit organizations
- Departments across UNH and other universities
- The NH Council on Developmental Disabilities (NH DDC) and the NH Disability Rights Center (NH DRC)

IOD Priority Areas

Our focus areas align with current and emerging national, regional, and state priorities related to individuals with disabilities. Although the work of the IOD is broad and diverse, a majority of IOD grants and programs are concentrated within Assistive Technology, Community Living & Employment, Health & Genetics, Inclusive Early Care & Education, and Behavioral Health & Wellness.

The IOD as a University Center for Excellence in Developmental Disabilities (UCEDD)

As a UCEDD, the IOD helps support people with developmental disabilities through education, research, and service. UCEDDs provide training, services, and technical assistance. They also conduct research and share important information. UCEDDs receive their core funding from the Administration for Community Living (ACL). Each UCEDD is associated with a university. There is at least one UCEDD in every U.S. state and territory.
Building Futures Together
The opioid crisis has had a lasting impact on mental health, and the need for trained professionals to care for our state’s most vulnerable children, youth, and families has never been higher. Building Futures Together is preparing paraprofessionals in healthcare and school settings to provide specialized enhanced care coordination to children and youth whose parents are impacted by opioid and other substance use disorders.

NH Leadership Series
“Leadership helped me find my voice. Advanced Leadership helped me recognize its importance.”
Did you know New Hampshire has over 1,000 trained advocates advancing disability-related issues? This year, the IOD’s New Hampshire Leadership Series launched an advanced series for graduates. Classes go beyond 101 learning to help graduates promote equity-based inclusive practices.

Facts & Figures
About one out of every eight New Hampshire residents report having a disability—that’s 12.9% of our state’s population! While federal agencies collect data and generate a variety of statistics about the population with disabilities in the United States, it is often difficult for local agencies, individuals with disabilities, and even seasoned researchers to find statistics. IOD’s annual Facts & Figures (pictured right) is the premier resource for New Hampshire policymakers, systems, and advocates. It gives readers access to essential data for policymaking, planning, research, and advocacy regarding the state’s population with disabilities.

Creating Connections NH Launches APGs for Youth in Recovery
The storm and stress of adolescence and young adulthood becomes increasingly challenging while maintaining recovery. This year, the IOD partnered with organizations to develop better models for Alternative Peer Groups (APGs) across the state. APGs provide positive peer support programs with prosocial, fun, substance-free activities for youth. Through community supports, young people learn how to engage in healthy lifestyle changes in a safe, socially-reinforcing environment.

NH-ME LEND
As public spaces closed across the country due to the pandemic, NH-ME LEND clinical partners were forced to shutter physical office spaces and turn to remote healthcare for clients with disabilities. This posed challenges to the NH-ME LEND program in providing high-quality clinical and leadership experiences for the incoming cohort. The program worked with clinics to continue to offer learning opportunities to trainees in a remote environment. Their effort ensured the program’s continued commitment to increasing the number of leaders in the Maternal and Child Health workforce.

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Andrew Strzykalski’s mother and father were battling more than the typical parental nerves when they dropped their son off at college for the first time this fall. Perhaps that explains how they spent their afternoon after leaving Andrew to settle into his new life as a student at UNH.

“I don’t think we left the campus after we dropped him off. We just sat in the parking lot all day,” Andrew’s mother, Barbara, admits.

The nerves Barbara and her husband Gerald were experiencing were atypical because Andrew isn’t a typical college student – he’s one of the first students to take part in the new UNH-4U program that offers fully immersive and inclusive higher-education opportunities to young adults with intellectual disabilities. Andrew is one of four students - three residential and one commuter - in the program’s inaugural cohort. UNH-4U is the only program of its kind in New Hampshire.

Andrew had never before spent extensive time away from home or had to navigate a complex daily schedule of classes and activities by himself. How would he handle such a significant change?

As it turns out, his parents wouldn’t be the only ones who resisted driving home from campus.

“A few weeks ago we had a meeting where we told him he had to go home for the holiday break, and he just shut down and wouldn’t participate in the rest of the call,” Barbara quips. “He just loves it there so much. He’s more verbal, he’s more outgoing, he’s more confident. He has really just come into his own.”

Such is the precise goal of the UNH-4U program, which has been more than five years in the making. The program opens doors to a mostly traditional college experience that was previously closed to students with intellectual disabilities. Students in the two-year program go through a separate admissions process and don’t earn a traditional degree, but are placed in classes that match their academic interests with the intent of starting them on a path to gainful employment after college. Along the way, they gain experience and life skills that are difficult to replicate in other scenarios.

“What’s going on with these students, it’s life-changing. They are experiencing a level of independence and academic success that many never dreamed possible.”

Excerpt from “UNH Today” article written by: Keith Testa | UNH Communications and Public Affairs

Photo (top right): Andrew Strzykalski’s dorm room.
Photo (top left): Andrew Strzykalski picks up his student ID.
Andrew Houtenville discusses the economic impact of COVID-19 on people with disabilities on NHPR’s “The Exchange.”

The IOD co-hosts a free “30th Anniversary of the ADA” webinar about disability representation in the media.

The U.S. Commission on Civil Rights report on subminimum wages cites the Annual Disability Statistics Compendium.

NH’s Living Well grant produces a training video for direct support professionals that focuses on the statement “I want my DSP to…”

Deb Brucker discusses job crafting in “Research in Focus: A Weekly Digest of New Research.”

The IOD receives a $2.5M grant to transform higher education in NH for young adults with IDD.

The NH DHP releases a report on how healthcare providers can make telehealth more accessible and responsive.

Therese Willkomm and OT students upcycle used campaign signs into assistive technology devices.

The NH-ME ECHO SCOPE series launches to help early intervention providers.

NH Magazine features Jennifer Rabalais and takes a closer look at ageism and the impact of COVID-19 on older people.

Makers Making Change acknowledges Therese Willkomm for her work making devices for people with disabilities during Women’s History Month.

CACL hosts the 2021 Age of Champions Health and Wellness Fair.

24 NH-ME LEND trainees visit with NH and ME congressional delegates to discuss the Home and Community Based Services Access Act.
The latest book by Therese Willkomm, PhD, Make Stuff and Love People: Assistive Technology Solutions in Minutes – Book III, is about the joy of creating and making thousands of different assistive technology solutions to maximize independence at home, workplace, school, and communities for individuals who experience various limitations. “It is the most comprehensive AT Makers book I’ve ever written,” says Therese. “I filled it with over 1,500 images, including over 500 QR codes for instant access to short YouTube videos and resources showing how to make the various AT devices.”

As the acute phase of the COVID-19 pandemic began to subside, experts reflected on the pandemic’s impact on employment in the U.S. nTIDE experts presented data that showed that people with disabilities have not only recovered from the setbacks of 2020 COVID-19 lockdowns, but they have also exceeded pre-pandemic levels of employment to reach new historic highs. This contrasts with their counterparts without disabilities who have yet to reach their pre-pandemic levels of employment.

On February 9, 2021, StatsRRTC at the Institute on Disability released key findings from the Annual Disability Statistics Compendium (ADSC). The annual report addresses critical gaps in national and state data related to people with disabilities by synthesizing complex data from numerous U.S. federal agencies into accessible formats. The Compendium is designed to make finding and using disability statistics easier for individuals working on legislative and other matters relating to persons with disabilities.

The National Center for START Services (NCSS) was approved for a $4.86 million funding award by the Patient-Centered Outcomes Research Institute (PCORI) for their study Evaluation of Telehealth Services on Mental Health Outcomes for People with Intellectual and Developmental Disabilities. Recently, telehealth services have become a more common, yet unproven, strategy for delivering mental health care to individuals with IDD. The project will compare an in-person to a telehealth-delivered crisis prevention program for youth and young adults with IDD.

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In April 2021, the National Center for START Services (NCSS) published the first edition of Integrated Mental Health Treatment Guidelines for Prescribers in Intellectual and Developmental Disabilities (IDD-MH Prescriber Guidelines). The primary aim of this project was to provide accessible best practice resources with a focus on integrated health and positive medicine for prescribers of persons with IDD and mental health needs.

The IDD-MH Prescriber Guidelines offers an overview of integrated health and psychopharmacological best practices in the treatment of patients with IDD and ASD. The guide is organized into five topic areas: 1) The Lived Experience Perspective: Working with Patients and Supporters; 2) Psychiatric Assessment Considerations; 3) Medical Assessment Considerations; 4) Best Practices in MH Diagnosis and Treatment; and 5) Prescribing in Mental Health Crises.

Prior to the development of this guide, focus groups were conducted with individuals with lived experiences, family members, clinicians, and prescribers. Focus group responses were analyzed and used to inform the development of the guide's content and vet accompanying resources. Thank you to all contributors, editors, and prescribers who served as volunteer reviewers.

The development of the IDD-MH Prescriber Guidelines and accompanying resources were made possible with funding from the WITH Foundation and field tested prior to publication. The aim of the editors is to continue to expand upon this foundation and provide additional best practice content to prescribers with periodic updates. Visit centerforstartservices.org to learn more.

About Our Research

The IOD makes significant contributions to the body of knowledge related to disability through its research and publications. 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 positively impact individuals with disabilities and their families.

Staff Highlight

“Many workers get stuck in a system that isn’t designed to protect them or support them to get better once injured. My hope is that, if we share meaningful information with our decision-making authorities about the magnitude of the problem, policies will change to better protect those workers at highest risk.”

Karla R. Armenti, ScD
Research Assistant Professor & Project Director
A Look at IOD’s Teaching

About Our Teaching
The IOD is dedicated to preparing tomorrow’s practitioners and leaders in disability-related fields through teaching. IOD faculty and staff design and implement innovative learning experiences, interdisciplinary teaching models, and programs of study that incorporate universal design principles, include the perspective and voice of those with lived experience, and leverage varied instructional methods and formats.

Staff Highlight
“Authenticity, honesty, reciprocity, and curiosity inform my teaching philosophy. Good teaching is like a ‘living thing’—it requires you to listen to and observe your students, try to understand how they are perceiving information, and then respond in a way that expands their understanding.”
Betsy Humphreys, PhD
Research Assistant Professor & NH-ME LEND Program Director

151 Teaching Activities
36 UNH Courses*
24 Guest Lectures
2 Training Curricula
91 IOD Workshops, Webinars, & Conferences*
86 Peer-Reviewed & Invited Presentations
*All-time high

A Look at IOD’s Dissemination

About Our Dissemination
Through 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 media and emerging technologies, with the goal of maximizing the reach, accessibility, and impact of its resources.

Staff Highlight
“Through dissemination, we can help change the landscape for individuals and families impacted by disability. Accessibility, representation, and authenticity is core to our marketing efforts. We aim to meet people where they are and in ways that encourage interest, action, and support.”
Romy Eberle
Marketing and Communications Manager

3,256 Social Media Engagements
167,791 Website Visits
53,031 Website Visitors
28,174 Facebook Reach
113,952 Twitter Reach

36 UNH Courses*
24 Guest Lectures
2 Training Curricula
91 IOD Workshops, Webinars, & Conferences*
A Look at IOD’s Service

About Our Service
The IOD creates more inclusive communities by providing local, regional, and national services that are evidence-based, progressive, and culturally relevant. Services include training leaders in disability-related fields, providing technical assistance to improve organizational and community capacities to include all citizens, and serving as a resource for policymakers.

Community Service Activities

- 178 Community Service Activities
- 22 UNH Committees & Commissions
- 62 Local, State, National Committees & Boards
- 46 Association Memberships
- 37 Editorial & Review Activities
- 11 Peer-Reviewed & Invited Presentations*
- 2,664 Technical Assistance Recipients
- 12,395 Technical Assistance Hours Provided*

Staff Highlight
“Service is about opening one’s heart, mind, and hands in order to help others without any thought to monetary gain, recognition, or the advancement of oneself in the work. It is simply a calling because it is the right thing to do for others and the communities in which we live.”
Kathy Francoeur, MEd
Project Director

Financial Breakdown & Funding Sources

- 41 Grants & Contracts
  - 16 Federal Grants
  - 6 State Contracts
  - 9 Federal Subcontracts
  - 10 Foundation Grants & Gifts

- 16 Federal Grants & Subcontracts
- 41 Grants & Contracts
- 6 State Contracts
- 9 Federal Subcontracts
- 10 Foundation Grants & Gifts

Total Budget $11,805,251*

- $5,492,290 Federal Grants & Subcontracts
- $4,217,533 Fee-For-service*
- $724,015 Foundation Grants & Gifts
- $415,660 Other Non-Grant Revenue

*All-time high
Leadership, Staff, & Awards

Management Team
Kelly Nye-Lengerman, PhD, Director
Matthew Gianino, MBA, Associate Director, Director of Communications
Andrew Houtenville, PhD, Professor, Director of Research
Jennifer Donahue, BA, Director of Finance and Administration
Betsy Humphreys, PhD, Assistant Research Professor, UCED Training Director, LEND Director
JoAnne Malloy, PhD, Associate Research Professor, Project Director
Lauren Quann, Director of Operations START
Kathy Pirie, Office Manager, Administrative Coordinator

Total Employees 99
- Full-time* 63
- Part-time 31
- Student 5

Faculty 9
- Tenure 1
- Clinical 1
- Research 7

Honors, Awards, & Fellowships 15

*All-time high

IOD’s Projects & Grants (July 1, 2020 - June 31, 2021)

>> Advanced Rehabilitation Research Training (ARRT)
A rigorous and collegial program designed by postdoctoral fellows used to expand the capacity of disability and employment research to address the ongoing employment gap between people with and without disabilities.

>> Assistive Technology New Hampshire (ATinNH)
NH’s lead agency for statewide assistive technology training, education, outreach, workshops, and services.

>> Building Futures Together
Prepares paraprofessionals in healthcare and school settings to provide specialized enhanced care coordination to children and youth whose parents are impacted by opioid use disorders (OUD) and other substance use disorders (SUD).

>> Career Self-Management through Job Crafting for People with Physical and Mild Cognitive Disabilities
A partnership between the IOD and Northeast Rehabilitation Hospital Network, Marsh Brook Rehab, and the UNH Office of Environmental Health and Safety to develop and test a new approach in assisting persons with disabilities to retain employment and seek opportunities for growth in the workplace.

>> Center on Aging and Community Living (CACL)
A collaboration between UNH’s IOD and the Institute for Health Policy and Practice (IHPP) for projects related to aging and long-term care.

>> Charting the LifeCourse in NH
An initiative developed by families to help individuals with disabilities and families create a vision for a good life, identify needs and supports, and discover what it takes to live the lives they want to live.

>> COVID-19 Vaccine Confidence Research
In an effort to improve COVID-19 vaccine access for older adults and people with disabilities in New Hampshire, the NH Developmental Disabilities (DD) Act partner organizations explore barriers to vaccine access and concerns about COVID-19 booster shots.

>> Creating Connections NH
A federally-funded project to develop and implement a system of care for youth, ages 12-25, with substance use disorders (SUD) and co-occurring mental health disorders (COD).

>> Disability Statistics and Demographics Rehabilitation Research and Training Center (StatsRRTC)
Bridges the divide between the producers and end users of disability statistics, thereby bettering the lives for people with disabilities.

>> Employment Policy and Measurement Rehabilitation Research and Training Center (EPM-RRTC)
Investigates the impact of federal and state policies and programs on employment

Photo (above): Deb Genthner, NH Leadership Series Coordinator, receiving a token from the IOD.
by examining new ways of measuring employment outcomes and facilitating the translation of research findings to guide policymaking and program administration.

>> Food Insecurity within New Hampshire
Provides briefs, reports, and manuscripts that describe trends in food insecurity within New Hampshire and for specific subpopulations within NH.

>> Health Disparities and Intellectual Disability
Informs efforts to improve the capacity of current health surveillance systems to track the health and healthcare of people with intellectual disabilities and increase the effectiveness of health-related practices, services, and programs that influence the lives of people with intellectual disabilities.

>> Health Disparities Project
Generates new knowledge about health access and health outcomes among subgroups of people with disabilities and translates and disseminates the findings for researchers, policymakers, and others.

>> HUD-Assisted Residents with Disabilities
By identifying gaps in quality of life, employment patterns, and health disparities, this research grant highlights areas that policymakers need to address.

>> Janet Krumm Disability and Media Lecture Series
An annual public lecture series that recognizes the power of information and the contributions of individuals who have used the media—written and visual—to create an understanding of the experience of disability.

>> Kessler Recent College Graduates Employment Survey
Addresses the gap in data related to ways college graduates with disabilities successfully navigate barriers to employment.

>> Kessler Supervisor Perspectives Employment Survey
Identifies ways that employers strive to hire and retain employees with disabilities by utilizing different approaches to successfully avoid or overcome barriers.

>> Living Well – NH Quality Frameworks
Utilizes strong and long-lasting partnerships with self-advocates, direct support professionals, state agencies, providers, families, and advocacy organizations to improve the supports and services for people with disabilities within the state.

>> Maternal Infant and Early Childhood Home Visiting (MIECHV) Evaluation
Evaluates New Hampshire’s fidelity to the implementation of the Healthy Families America home-visiting model, as well as the effect of the model on family outcomes.

>> Multi-tiered System of Support (MTSS)
A data-driven behavioral support and improvement framework that consists of three levels, each specifically designed to prevent disruption and address the behavioral support needs of students at risk of school failure.

>> National Center for START Services
A national initiative that works to strengthen efficiencies and service outcomes for individuals with intellectual and developmental disabilities (IDD) and mental health needs in the community.

>> National Research Consortium on MHIDD
Partnering with stakeholders in the prioritization, development, and dissemination of best-practice research to improve the quality of care delivered to those with IDD across the country.

>> New England Regional Genetics Network
Advances the health and well-being of individuals with genetic conditions by connecting them with genetic services, and educates professionals to improve systems of genetic care while also supporting families in New England.

>> New Hampshire Disability and Health Program
Improves the health and quality of life of people with disabilities in NH by implementing evidence-based strategies to reduce unmet health needs, increasing access to preventive health care, and facilitating the adoption of healthy behaviors.

>> New Hampshire Disability RAPP Sheet
A semi-annual, collaborative publication featuring the latest in disability research, advocacy, policy, and practice produced collaboratively by the New Hampshire Disabilities Rights Center, the Institute on Disability, and the New Hampshire Developmental Disabilities Council.

>> New Hampshire Wraparound
A youth- and family-driven process that supports children or youth with significant emotional or behavioral challenges and their families.

>> NH Children’s Behavioral Health Workforce Development Network
Creates hope and improved outcomes for children, youth, young adults, and their families by convening, promoting, developing, implementing, and disseminating interdisciplinary workforce development activities.

>> NH Leadership Series
A training series that provides nonpartisan, state-of-the-art information and strategies to effectively impact local and state organizations on issues related to individuals with disabilities and their families.

>> New Hampshire-Maine Leadership Education in Neurodevelopmental Disabilities Program (NH-ME LEND)
A collaborative project between the IOD at UNH, Center for Community Inclusion and Disability Studies/UCED at the University of Maine, and Dartmouth Hitchcock Medical Center that improves the health of children and youth with neurodevelopmental disabilities by preparing leaders to enter the field of maternal and child health.

>> Occupational Health Surveillance Program
Provides meaningful statistics to identify priority occupational safety and health issues in New Hampshire.

>> Raising Awareness to Increase Safety in Employment (RAISE)
A training curriculum designed for teaching workers with intellectual and developmental disabilities about health and safety on the job.
>> Resilience, Empowerment, and Natural Supports for Education and Work (RENEW)
A structured school-to-career transition planning and individualized wraparound process for youth with emotional and behavioral challenges.

>> Staying Safe at Work Training
Addresses the shortage of occupational health and safety training for workers with Intellectual and Developmental Disabilities (IDD) by offering NH disability service providers the Staying Safe at Work curriculum.

>> Transition Program for Students with Intellectual Disabilities (TPSID) & UNH-4U
Provides inclusive postsecondary experiences and education to students with intellectual disabilities in New Hampshire.

>> Understanding Food-Related Hardships Among Older Americans: Evidence from the Panel Study of Income Dynamics Project
Identifies and explores the prevalence of food insecurity in households with persons age 60 and older.

>> UNH TIPP - Advanced Graduate Certificate in Trauma-Informed Schools and Communities Project
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.

Offices

Durham Office
10 West Edge Drive, Suite 101
Durham, NH 03824
Voice: 603.862.4320 | Relay: 711
Fax: 603.862.0555
Email: contact.iod@unh.edu

Pettee Hall Office - NH-ME LEND
55 College Road, Room 103
Durham, NH 03824
Voice: 603.862.0561 | Relay: 711
Fax: 603.862.0034

Concord Office
57 Regional Drive, Unit 8
Concord, NH 03301
Voice: 603.228.2084 | Relay: 711
Fax: 603.228.3270

Professional Development Center
57 Regional Drive, Unit 8
Concord, NH 03301
Voice: 603.228.2084 | Relay: 711
Fax: 603.228.3270