For over 50 years, the Indiana Institute on Disability and Community has been at the forefront of promoting inclusivity and advocating for the rights of individuals with disabilities and their families through innovative research, education, and service contributions in Indiana.
Friends and Colleagues:

For over half a century, the Institute has proudly served the state of Indiana and Hoosiers with intellectual, developmental, and other disabilities. In this time, many changes have affected this group, and the biggest and most impactful is the recognition that people with disabilities have the same rights as every American. At the Indiana Institute, we’ve been fortunate to see these changes close-up – the emergence of new systems that provide education and community supports, the expansion of civil rights protections, the closing of state-run institutions, and many more. We’ve also witnessed firsthand as people with disabilities, including those with significant challenges, realized their rights to receive quality education, live and work in the community, recreate and socialize as they choose, and lead self-determined lives.

Today, the systems we operate in are varied, complex, and ever changing. By leaning into these challenges, the Institute and its seven centers serve as important partners in navigating the systems changes underway. Through our research, education, and technical support, we work with individuals, families, professionals, organizations, and service systems to overcome the complexity and challenges to put good ideas into everyday practice. And by engaging and listening to the diverse voices of Hoosiers with disabilities and their families, we seek to bring your voices to the forefront to inform what we do and how we do it.

Of course, the Institute does not achieve this on its own. It is through a rich network of new and long-term partnerships with individuals, organizations, and state agencies that makes our work possible. We are immensely grateful for these partnerships, and we look forward to continuing the advancements for Hoosiers with disabilities and their families.

The result, as exemplified in this annual report, is a vibrant organization with a deep, state-wide reach and impact. Looking to the future, where many opportunities and challenges remain, we look to leverage these successes to further advance opportunities for Hoosiers with disabilities. We look forward to working with you to make this possible.

Best Regards,

Derek Nord, PhD
Director

Imagine communities that facilitate and support equitable access to a desirable life for all people.

Research Centers at the Indiana Institute

- Center for Collaborative Systems Change
- Center for Health Equity
- Center on Community Living and Careers
- Center on Education and Lifelong Learning
- Early Childhood Center
- Eppley Institute for Parks and Public Lands
- Indiana Resource Center for Autism

Institute staff Advance Improvement in policy and practices in disability through five areas of emphasis...

- Competitive Integrated Employment
- Decisional Supports
- Education Across the Lifespan
- Health, Wellness, and Recreation
- Medicaid Home and Community-Based Services

A Community Where You Belong
Advancing Equity for All Hoosiers

The Indiana Institute on Disability and Community (IIDC), the federally designated University Center for Excellence in Developmental Disabilities (UCEDD) in Indiana, is committed to advancing equity for all Hoosiers. As a bridge between Indiana University, the state, and the nation, IIDC strives to ensure that individuals with disabilities are valued and fully included in every aspect of community life. For over 50 years, the IIDC has provided research, education, and best practices to the community with the goal of promoting inclusion and protecting the rights of people with disabilities and their families.

In addition to its mission and values, the IIDC has federally mandated “core functions” that it implements to achieve its goals. These functions include interdisciplinary pre-service preparation of students, providing training and technical assistance to individuals with disabilities and their families, professionals, policymakers, and others through demonstration and model activities, conducting research, evaluation, and public policy analysis, and disseminating information to multiple audiences.

By the Numbers

The Institute’s research to practice initiatives support the advancement of applied research, evaluation, and public policy; outreach that is community-oriented and state-wide; technical assistance activities that are collaborative, systematic, and results driven; and educational preparation that supports the pre-service and in-service training of professionals to become leaders in the field.

114,945 People Impacted
7,811 Hours of Training and Technical Assistance Provided
171 Boards and Committees
10 State and National Awards

<table>
<thead>
<tr>
<th>Research</th>
<th>Service</th>
<th>Scholarship</th>
<th>Education</th>
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<tbody>
<tr>
<td>90</td>
<td>114,945</td>
<td>124</td>
<td>898</td>
</tr>
</tbody>
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projects ranging in topics across the lifespan
people impacted at 535 events
products produced by Institute professionals
university students impacted by the Institute

34 Early intervention and education
29 Promotion and accessibility
15 Health promotion and equity
7 Self-advocacy and families
5 Employment

45,379 Professionals/paraprofessionals
34,289 People with disabilities
25,851 Family members/caregivers
6,619 General public
1,999 Students
727 Community/state/national partners
81 Legislators/policymakers

47 Electronic and web-based products
27 Reports and monographs
15 Academic courses and distance learning modules
14 Conference presentations
13 Newsletters, pamphlets, brochures, fact sheets
7 Book chapters and peer-reviewed journal articles
1 Dissertation

A special thank you to the IIDC Advisory Council members: Derek Nord, Chair, Kate Barrow, Sylvia Brantly, Courtney Clark, Frank Epperson, Shawn Fulton, Stacey Haight, Leah Helweging, Sarah Hurwitz, Melissa Keyes, Mary Ann Lapenta, Kate McQueen, Cori Mitchell, Chris Myers, Cynthia Nassim, Amber O’Haver, Jordan Oliver, Jen Piatt, Abe Shapiro Chris, Stroiguiludis, and Karen Vaughn.

In memoriam of Council member David Carter who passed June 23, 2023.
Early Childhood

Infant/Toddler Mental Health

The Early Childhood Center (ECC) was awarded a Mental Health Champion grant from the Administration for Children with Disabilities (AEDC) and Centers for Disease Control and Prevention (CDC) to explore early childhood mental health in Indiana. Dr. Katie Herron, ECC director, led the project and compiled data from over 20 existing state level needs assessments along with other available state level data and developed a report. This data was organized according to the three components of early childhood mental health that refer to a child’s ability to:

- Form close and secure adult and peer relationships;
- Experience, manage, and express a full range of emotions; and
- Explore the environment and learn.

The report emphasized the need for increased coordinated early childhood mental health support with accompanying evaluation.

The report was refined in collaboration with a state level advisory group formed during an inaugural Summer 2022 Infant Toddler Mental Health Summit. Additional joint efforts included the Indiana Home Visiting Collaborative to share progress and receive recommendations. These recommendations were disseminated through media interviews and via social media.

A series of four webinars for professionals were developed highlighting data from the report while another featured the Infant Toddler Mental Health Endorsement in Indiana with a panel of practitioners and educators sharing information designed to build awareness among service providers in the state. The third webinar featured a collaboration with Indiana’s CDC “Learn the Signs. Act Early.” Ambulants will offer 70% of those facing social emotional developmental milestones and basic information about early childhood mental health can support families and caretakers with creating healthy spaces at the ways infants and toddlers interact with others. The final webinar was a collaboration with state level childcare leaders that spotlighted new state initiatives supporting childcare professionals to address challenging behaviors, coaching, and supporting families.

The report emphasized the need for increased coordinated early childhood mental health support with accompanying evaluation.

Supporting Early Diagnosis and Early Intervention for Young Children with ASD or Behavioral Challenges

Autism spectrum disorders now affect 1 in 36 individuals, with over 70% of those diagnosed experiencing co-occurring challenges, including external behavior issues, anxiety, depression, and other mental health issues. Supporting children with these challenges can be difficult, particularly in early childhood programs where mental health concerns can surface. Although commonly used, Applied Behavior Analysis (ABA) techniques, and some families may prefer alternative approaches. A collaborative project among the efforts of the Indiana Resource Center for Autism (IRCA) and the Indiana Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program will provide families of young children and early childhood professionals with practical tips and consumer friendly training and coaching to aid in early diagnosis. Written materials will be translated into Spanish and posted on the IRCA and Act Early Indiana websites. The project aims to reach marginalized families who may have difficulty accessing these resources. Family input will be sought to ensure that the materials are practical and family friendly.

Early Intervention Conference

The Early Childhood Center (ECC) collaborates annually with the Bureau of Clinical Development Services (BCDS) and Indiana Children’s Network (ICN) to develop a virtual conference for early intervention providers and families statewide. After two years of virtual conferences due to COVID, this year’s conference is scheduled for June 23, hosted by 800 participants, speakers, and exhibitors. Conference keynote speakers will address the importance of collaboration, belonging, health equity, and the skills needed to have difficult conversations. Breakout topics will center around practical topics such as addressing challenging behaviors, coaching, and supporting families with children on the autism spectrum. To increase participation, the conference offered a keynote session, both in-person and virtual, for those who were unable to attend in-person. The panel addresses this annual opportunity to showcase best practices in a collaborative setting in which providers feel connected to their peers.

Additional Featured Projects

Dream Big Start Early Podcast

The Early Childhood Center (ECC) received a grant from the Wal Dist. Foundation of Fort Wayne, Indiana, to support the development of a micro-learning curriculum for families of young children with disabilities. This curriculum will address two critical information gaps that impact families in early childhood. The first focuses on the importance and development of high family expectations. Research has shown that family expectations influence early childhood outcomes. The other gap is around understanding inclusion and that inclusive environments are beneficial to children with and without disabilities. Unfortunately, early childhood systems do not clearly and consistently communicate information and parent education around inclusion to families. Micro-learning will be developed that will be accessible to a wide variety of families, include videos made by families, and will be piloted in Northeast Indiana in collaboration with early childhood educators and family support organizations in that area.

Family Guided Routines Based Intervention

Family Guided Routines Based Intervention (FGBI) is a well-established best practice in early intervention. Over 155 providers have completed an online training experience providing information about FGRBI. More than 80 providers from 13 different agencies have completed, or are continuing to participate, in a statewide FGRBI coaching program in collaboration with Florida State University. These providers are learning how to utilize caregiver coaching to support parent and child interaction and coaching to support parent and child interaction. Coaching is available through a state level advisory group formed during an inaugural Summer 2022 Infant Toddler Mental Health Summit. The Center and First Steps in adopting FGRBI as a statewide model of implementation science, the Center and First Steps’s work will create systemic changes to support the adoption of caregiver coaching, a well-established best practice in early intervention. Over 155 providers have completed an online learning experience providing information about FGRBI. More than 80 providers from 13 different agencies have completed, or are continuing to participate, in a statewide FGRBI coaching program.

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Many families are impacted by autism spectrum disorder and intellectual disabilities (ASD/ID), and the overall health and wellness of family caregivers can have a significant impact on family functioning. The Indiana Institute was funded by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) to examine issues related to family caregivers. This work has produced numerous products and outputs including two peer reviewed publications and national and international presentations.

Through this project’s funding, IIDC researchers sought to understand the health and work-related experiences of caregivers of autistic children and autistic children with intellectual disability (ASD/ID). The project examines whether there were economic engagement and health inequities between these caregivers and those who have children without ASD/ID. In order to complete the work, researchers used the National Household Interview Survey (NHIS), an annually national representative cross-sectional household interview survey conducted by the Centers for Disease Control and Prevention (CDC).

Through rigorous quantitative statistical methodology, the team found that parent caregivers of autistic children and autistic children with intellectual disability (ASD/ID). Through this project’s funding, IIDC researchers sought to understand the health and work-related experiences of caregivers of autistic children and autistic children with intellectual disability (ASD/ID). The project examines whether there were economic engagement and health inequities between these caregivers and those who have children without ASD/ID. In order to complete the work, researchers used the National Household Interview Survey (NHIS), an annually national representative cross-sectional household interview survey conducted by the Centers for Disease Control and Prevention (CDC).

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ICTQ Collaboration

Information sharing can be the catalyst to successful project implementation at the Indiana Institute. The collaboration between the IIDC’s Early Childhood Center (ECC) and the Center on Teacher Quality (ICTQ) resulted in successful project implementation of a validated survey tool that measures parents’ perceptions of the family-school relationship. The work of ICTQ to support districts to improve family engagement. Using the Indiana Department of Education’s (IDOE) Family-Friendly Schools Initiative as a collaborative initiative, ICTQ staff implemented the survey in six out of seven school districts. Results indicate that general parents experience a welcoming climate but felt that power to make school policy, program, or curricular decisions could be shared more effectively. District implementation teams will analyze results and include action steps in their implementation plans going forward. Additionally, ECC staff designed a family engagement component for ICTQ trainings involving teachers and principals around the Dual Capacity-Building Framework for Family-School Partnerships. Additional Featured Projects

NCI Child Family Survey

The Indiana Institute conducted the Child Family Survey (CFS) in 2022 as part of its ongoing partnership with the National Core Indicators (NCI) project. NCI collects valid and reliable data about the performance of public IDD systems through a collaboration between the National Association of State Directors of Developmental Disabilities (NASDD), the Human Services Research Institute (HSRI), and state IDD agencies. The CFS data is collected annually in a cross-sectional survey of the state of services for children with intellectual and developmental disabilities (IDD) who live in the family home. The Institute surveyed 1,500 families in Indiana to elicit their perceptions and concerns about employment, disability rights, service planning, community inclusion, health, and safety. Results of both the state and national picture of services and supports will be distributed through reports and academic literature. The findings of the CFS will provide families, researchers, policymakers, and practitioners valuable takeaways to improve the service system for children with IDD and their families.

Educating the Whole Child Summit

Since the inaugural Summit in 2019, the Indiana School Mental Health Initiative (ISMHI) has hosted an annual Summit for students, teachers, school leaders, community organizations, and mental health professionals from across Indiana. The Summit is a day-long conference to share evidence-based practices to create the best conditions for learning for all of Indiana’s public school students, the recognizing that students must experience well-being to achieve their full academic potential. From the first sold-out Summit in 2019, ISMHI has continued to offer inspiring and engaging keynotes, breakout sessions, activities, and exhibits with consistent attendance of over five hundred attendees each year for a day by day learning and networking. Preservice teachers are offered scholarships to attend; most recently high school students have been in attendance to share their stories and their work to reduce the stigma of mental health. Momentum for this event continues as well as being recognized as an imperative piece of the educational process for students.

Camp Yes And

Camp Yes And, a project of the Center on Education and Emotional Learning (CEEL), is dedicated to fostering equity and inclusion in education. The camp offers a unique combination of education professional learning and support for neurodiverse youth to make social connections. The curriculum focuses on integrating improvisational theater techniques into academic and social-emotional learning. Since its founding in 2015, Camp Yes And has served 92 youth and 66 educators directly, with an estimated impact on thousands of students across the country. “Camp just perfected the way I talked home, a safe haven,” said a participating student. An educator reported, “Several times this week, I found myself wishing I was more like them. They are brilliant, courageous, and compassionate.”
Young Adulthood

Family and Social Services Administration Grant

The Division of Disability and Rehabilitative Services (DDRS) of the Family and Social Services Administration (FSSA) awarded the Indiana Institute on Disability and Community (IIDC) a training grant for the years 2022-2024. In collaboration with leadership from Vocational Rehabilitation (VR) Services and the Bureau of Disabilities Services (BDS), the IIDC team provided training to VR staff and is working to revise and develop new courses for case managers as well as organize a large-scale, state-wide conference for DDSR staff.

The Center on Community Living and Careers (CCLC) leads the Vocational Rehabilitation (VR) Staff Training component. As part of this grant, the Center meets regularly with VR leadership, has conducted a needs assessment for VR staff, and has provided training on several topics, including motivational interviewing, career planning, socially responsive communications, and legal issues. The experience of developing training materials will be leveraged for the conference. This includes resources such as the IIDC’s Indiana Disability History Project, Supported Decision-Making webinars, and resources on Charting the LifeCourse (northern, central, and southern) covering urban, suburban, and rural communities and is offered in an online format each winter. FEAT offers individual and group support to participants to enhance their understanding of the following topics: Building an Inclusive Workforce – 27 attendees per session (in person and online) with projections expected to reach at least 100 participants annually. In 2024, the online FEAT training will be available in Spanish to reach a more diverse audience.

A five-phase strategic training plan guides the case manager training initiative which is rooted in reflections of strengths, gaps, and observations accumulated over the past years.

FEAT Expands to Statewide Level

Family Employment Awareness Training (FEAT) is an adaptable, evidence-based program designed to help transition-age students (ages 14-22) with disabilities, their families, and professionals understand customized, competitive employment. With Pre-Entry Transition Services (PETS) authorized funds from Indiana Vocational Rehabilitation (VR) Services, the Department of Community Affairs and Careers (CCCLC) expanded Indiana FEAT activities statewide. To reach new stakeholder states, FEAT offers a different community annually and in three regions (northern, central, and southern) covering urban, suburban, and rural communities and is offered in an online format each winter. FEAT providers offer individual and group support to participants to enhance their understanding of the following topics: Building an Inclusive Workforce – 27 attendees per session (in person and online) with projections expected to reach at least 100 participants annually. In 2024, the online FEAT training will be available in Spanish to reach a more diverse audience.

Statewide FEAT trainings are offered in each of the 85 counties in Indiana, including urban, suburban, and rural communities and are offered in an online format each winter. FEAT providers offer individual and group support to participants to enhance their understanding of the following topics: Building an Inclusive Workforce – 27 attendees per session (in person and online) with projections expected to reach at least 100 participants annually. In 2024, the online FEAT training will be available in Spanish to reach a more diverse audience.

Additional Featured Projects

In April 2023, the Center on Community Living and Careers (CCLC) introduced the National Learning Academy (NLA), a virtual education platform for social services professionals. The NLA offers self-paced training for professionals assisting individuals with disabilities in employment. Courses provide education on working with key disability populations along with evidence-based strategies to support individuals with disabilities in employment or postsecondary education. The NLA launched with four courses: Mental Health conditions, including anxiety disorders, bipolar disorders, personality disorders, and schizophrenia spectrum and other psychotic disorders. Other courses include: Continuing Education credit, and Community Rehabilitation. This continued emphasis on professional development underscores a commitment to providing the most comprehensive and effective support for individuals with disabilities.

A five-phase strategic training plan guides the case manager training initiative which is rooted in reflections of strengths, gaps, and observations accumulated over the past years.

CCLC has delivered this training in person and virtually, with an average of 150 participants per topic. Looking ahead to the professional development schedule for 2023-24, the Center plans to include training for VR staff that focuses on working with individuals with anxiety disorders, schizophrenia, and neurological disorders. This continued emphasis on professional development underscores a commitment to providing the most comprehensive and effective support for individuals with disabilities.

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Where access is improved and expanded to provide opportunities for competitive integrated employment and community living.
Disability in Clinical Trials Project

It is well documented that people with disabilities are more likely to have chronic health conditions than their counterparts without disabilities which indicates greater needs for medication among those with disabilities. Through the Disability in Clinical Trials Project, the Center for Health Equity (CHE) works to promote equity, diversity, and inclusion in clinical drug trials. Given the underrepresentation of disadvantaged populations in medical research, people with disabilities might not be well represented in clinical drug trials despite their poorer health conditions and greater health care needs compared to those without disabilities. CHE staff examined potential challenges and barriers to inclusion of adults with disabilities in clinical drug trials through a review of the policies and regulations governing clinical trials and in discussion with a representative from an Indiana University research compliance office.

Some of the identified practices and barriers included: stringent procedures for obtaining informed consent for people with disabilities’ participation; lack of experience and training about individuals with disabilities among clinical research staff; research staff’s concerns about including those with disabilities due to potential additional work and complexity pertaining to informed consent, and safety issues related to co-morbidity; and the logistics of clinical trials including those with disabilities due to potential additional work and complexity pertaining to informed consent, and safety issues related to co-morbidity; and the logistics of clinical trials creating barriers to participation, including time constraints, transportation, and accessibility.

CHE staff also conducted a scoping review of peer-reviewed literature to describe recent research activity that examined the inclusion of adults with disabilities in clinical trials in drug development. The scoping review did not reveal any guidance pertaining to the inclusion of adults with disabilities in clinical drug trials. CHE staff carried out another review of articles that did not meet the scoping review criteria but compared to those without disabilities. CHE staff examined potential challenges and barriers to inclusion of adults with disabilities in clinical drug trials.

Additional Featured Projects

Vaccination Outreach Hub Project

Vaccination is an effective way to protect individuals against infectious diseases. With funding from the Association of University Centers on Disability (AUCD) in the Center for Health Equity (CHE) serves as a Local Vaccine Management Regional Hub for the Centers for Disease Control and Prevention’s (CDC) Project 4 of (RFA) Response (Indianapolis, Indiana, Michigan, Minnesota, Ohio, and Wisconsin). The project promoted vaccine outreach and increased vaccination rates among people with disabilities and their families as well as paid caregivers. To this end, staff from CHE and Indiana Resource Center for Autism (IRCA) collaborated to develop a vaccination webinar and developed fact sheets and vaccination promotional videos in English, Spanish, and American Sign Language. An advisory committee consisting of disability advocates from FEMA’s Region 5 provided guidance to promote vaccination outreach in the states. The promotional materials focused on personal vaccination experiences, the importance of vaccinations, and the unique challenges of people with disabilities in receiving equitable access to vaccines.

Additional Featured Projects

Study on the Experiences of LGBTQ People of Color in Higher Education

A collaboration between researchers from the Williams Institute at UCLA School of Law, the Point Foundation, and the Center for Health Equity (CHE) investigated the experiences of people of color (POC) including those with disabilities in higher education. The study used data from a nationally representative sample aged 18 to 40 (N = 1079) and discovered that LGBTQ POC encounter more barriers to academic success than their white LGBTQ peers. This was due to lifetime experiences of anti-LGBTQ bullying, harassment, and unfair treatment that prevented them from receiving their desired education, training, or degrees. Moreover, one third of LGBTQ POC received little or no information about college applications from high school counselors and teachers. LGBTQ POC also experience bullying, harassment, and assault in college at similar rates to white LGBTQ students and more than non-LGBTQ peers of color. The study concluded that it is crucial for educational institutions to create and maintain an environment that fosters resources and support for LGBTQ students of color.

U.S. Play Coalition

In the spring of 2023, the U.S. Play Coalition, part of the Department of Parks, Recreation, and Tourism Management at Clemson University, announced that the IIDC is a Play Equity Hub (PEH) for the department’s Play Equity Hub Program. The IIDC was selected as a PEH based on its demonstrated dedication to play and youth empowerment. The IIDC has a track record of advocating for play as a fundamental right and has been a leader in promoting play equity. The IIDC’s work aligns with the vision and mission of the PEH Program and its focus on advancing equity in play. The PEH Program is designed to help organizations and communities create and sustain equitable play environments. The IIDC has been involved in the development and implementation of play policies and programs and has a strong commitment to play equity. The IIDC’s award was based on its demonstrated leadership in play advocacy and its commitment to creating equitable play opportunities for all children and young people. The IIDC will use the award to continue to advance play equity and to support the work of the PEH Program in the region.