



# 2019 ANNUAL REPORT



INDIANA INSTITUTE ON  
DISABILITY AND COMMUNITY

Visionary solutions in  
disability and community  
through research,  
education, and service  
in Indiana since 1970.



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# From Our Director

Friends and Colleagues:

Change is inevitable, and anyone engaging with Indiana's public systems in recent years knows this all too well. In the last two years alone, systems that educate, serve, and support Hoosiers with disabilities across the lifespan began rethinking their approaches. Some systems are already initiating major reforms. Changes underway, among others, include the integration of new approaches in early childhood services, new graduation requirements targeting skills to prepare students for the labor force and higher education, redesigning of Medicaid Home and Community-Based Services, and an expansion of less restrictive alternatives to guardianship. Common among these is a push for greater individualization, increased service flexibility and choice, and greater opportunities for people with disabilities to be included in their communities.

At the Indiana Institute on Disability and Community, we have been at the forefront of advancing and supporting many of these systems changes. With our deep expertise and knowledge about the state and the public systems, and our capacity to conduct research and evaluation, train and educate, convene and engage key stakeholders, and scale-up best practices, the Institute remains steadfastly committed to supporting the state to ensure all Hoosiers are included.

At the Institute, we also recognize that Indiana is a culturally and linguistically diverse and rich state. As such, it is imperative that we, through our day-to-day work, acknowledge and embrace this diversity. In the last year, we at the Institute committed to expand our professional and organizational capacities to more effectively include and serve diverse communities. As a partner in statewide systems change, we are also committed to using these capacities to ensure we are responsive to the varying needs of the diverse communities in which we operate.



The future is bright for people with disabilities in Indiana and the changes underway today will serve as the critical foundation. Though there is much work to do across the state, I am confident that with Indiana's strong and effective self-advocates, families, advocates, professionals, and policymakers, people with disabilities will have greater opportunities to lead meaningful lives in the community.

I invite you to take a moment to read this annual report that provides a glimpse into our work and impact for 2018-19. To learn more in-depth about the Institute's research to practice activities, please visit our website at [www.iidc.indiana.edu](http://www.iidc.indiana.edu).

Sincerely,

Derek Nord, Ph.D.  
Director

## A LIFESPAN APPROACH TO DISABILITIES

IMAGINE COMMUNITIES THAT FACILITATE AND SUPPORT EQUITABLE ACCESS TO A DESIRABLE LIFE FOR ALL PEOPLE



Where family-community partnerships provide all families the supports they need to nurture, teach, and advocate for their children.



Where the capacity of educational systems and universally designed services meet the needs of all students.



Where access is improved and expanded to provide opportunities for competitive integrated employment and community living.



Where individuals participate in all facets of community life and have choice and control over their health and independence.

### RESEARCH CENTERS AT THE INDIANA INSTITUTE

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

### INSTITUTE STAFF ADVANCE IMPROVEMENT IN POLICY AND PRACTICES IN DISABILITY THROUGH...

- Advocacy
- Coalition Development
- Family Engagement
- Information Dissemination
- Pre-Service Education and Preparation
- Research, Evaluation and Policy Analysis
- Training & Technical Assistance

A COMMUNITY WHERE YOU BELONG

# A Foundation of Excellence

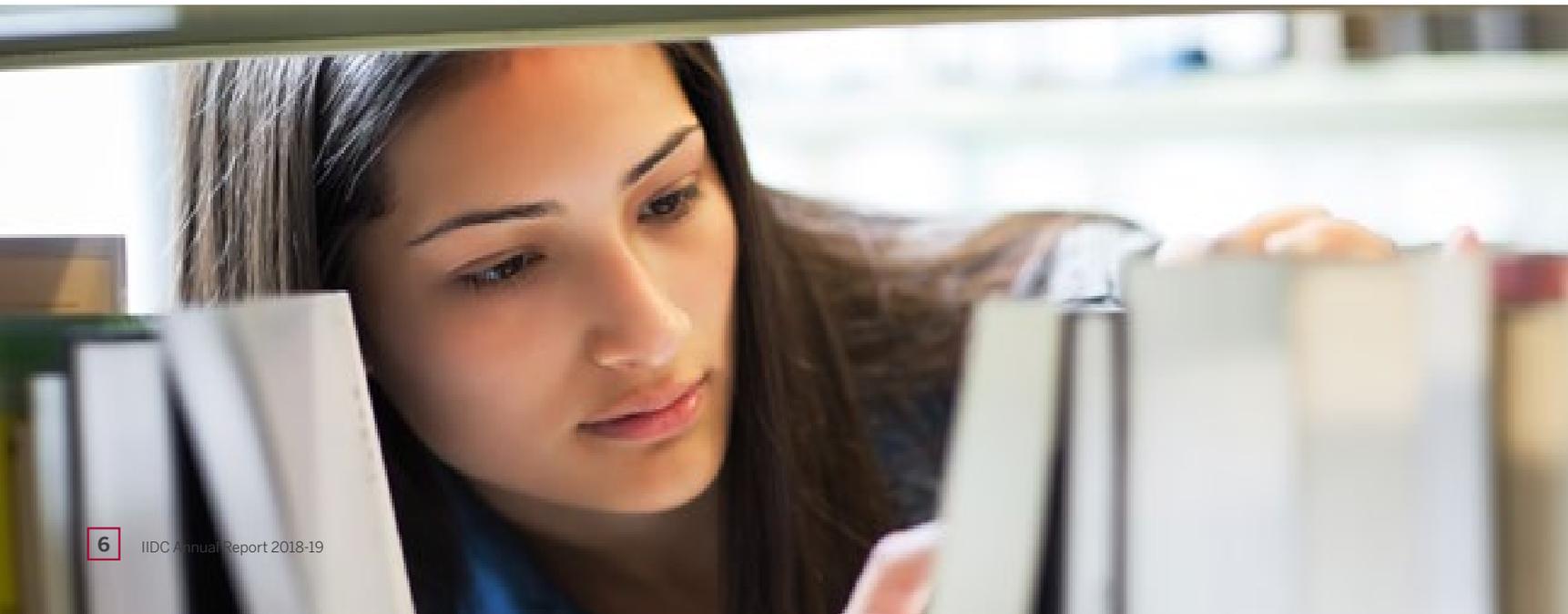
The Indiana Institute on Disability and Community (IIDC), Indiana's University Center for Excellence in Disabilities, has fostered a foundation of excellence for community investment in developmental disabilities since 1970. Our mission is to work with communities to welcome, value, and support the meaningful participation of people of all ages and abilities through **research**, **education**, and **service**.

Our work crosses the lifespan and is conducted across six centers and an Indiana University disability-focused library accessible to all state residents.

## Advancing Improvement in Policy and Practices in Disability

The Indiana Institute is a bridge that connects the university to the broader community through the sharing of ideas and innovations to improve communities and lives. The Institute's work achieves this through:

- **Advocacy:** Advancing effective policy and best practices by informing and educating decision makers.
- **Coalition Development:** Developing collaborative solutions by connecting and convening diverse community stakeholders.
- **Family Engagement:** Supporting families through partnerships among educators and human service providers to strengthen learning, independence, and community connections.
- **Information Dissemination:** Communicating and sharing information and research findings with broad constituencies over various mediums.
- **Pre-Service Education and Preparation:** Supporting the training of professionals to become leaders and prepare future practitioners to implement best practices in the field.
- **Research, Evaluation and Policy Analysis:** Conducting disciplined inquiry to test and improve policies, programs, and practices.
- **Training and Technical Assistance:** Building capacity to support community members and professionals in applying specific skills and best practices.



# 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.

**69,525**  
PEOPLE IMPACTED

**7,738**  
HOURS OF TRAINING PROVIDED

**144**  
BOARDS & COMMITTEES

### RESEARCH



52 projects ranging in topics across the lifespan

- 29 Early intervention and education focused projects
- 10 Employment focused projects
- 7 Health promotion and equity projects
- 6 Self-advocacy focused projects

### SERVICE



68,515 people impacted at 563 events

- 58,799 Professionals/paraprofessionals
- 7,225 Family members/care-givers
- 1,393 People with disabilities
- 628 Students
- 429 General public
- 41 Legislators/policymakers

### SCHOLARSHIP



104 products produced by Institute professionals

- 29 Reports and monographs
- 36 Newsletters, pamphlets, brochures, fact sheets
- 13 Academic courses and distance learning modules
- 11 Conference presentations
- 9 Electronic and web-based products
- 3 Book chapters and peer-reviewed journal articles
- 2 Press communications
- 1 Dissertation

### EDUCATION



90 university students impacted by the Institute

- 61 Students taught during academic courses in 2018-2019
- 183 Credit hours generated by IU students
- 14 Masters and doctoral level students mentored or advised
- 15 Interdisciplinary trainees
- 5 Academic courses taught

Thanks to our IIDC Advisory Council members: Dawn Adams, Sylvia Brantley, David Carter, Christine Dahlberg, Frank Epperson, Shawn Fulton, Sharon Hauss, Stacey Heath, Leah Helvering, Mary Ann Lapenta, Kate McQueen, Cori Mitchell, Chris Myers, Cynthia Nassim, Derek Nord, Amber O'Haver, Chris Strogiludis, Karen Vaughn.

Where family-community partnerships provide all families the supports they need to nurture, teach, and advocate for their children.



# Early Childhood

## Professional Development Strategies: Best Practice Coaching

Research indicates that professional development (PD) intended to teach new skills requires intensive ongoing support – workshops alone are not sufficient. Recognizing this, the Early Childhood Center (ECC) adopted and integrated Practice-Based Coaching (PBC) strategies into its PD efforts this past year, including work with preschool teachers to adopt inclusive early education practices and with individual First Steps agencies to adopt family guided home visiting practices. PBC is an evidence-based model that supports the acquisition and implementation of new practices by providing individualized and continuous coaching support.

Following face-to-face workshops introducing new evidence-based practices, ECC staff facilitated the following components of PBC. First, early intervention and education practitioners completed a self-assessment of their knowledge and implementation of the target practices, while their coaches or mentors conducted an initial assessment by observing the practitioners during home visits or classroom activities. Next, the coach and 'coachee' met to jointly develop an individual PD goal and action plan specifying the actions the practitioner would take in implementing the new practices, the resources they might need, and the level of support they would receive from their coach/mentor. Afterwards, the coach and practitioner would engage in monthly observation/meeting times, in which the coach observed the practitioner's efforts followed by a meeting to reflect, give and receive feedback, and formulate the next action plan. The cyclical nature of the PBC process ensured that the desired outcomes of coaching were regularly reviewed and revised.

The Center implemented PBC differently with the two early childhood programs. In our work with preschool educators, ECC staff were the coaches and provided in-classroom supports, including modeling targeted practices and/or providing feedback during a lesson. In our work with the First Steps agencies, agency staff took on the role of coaches/mentors and implemented the PBC strategies themselves. ECC staff "coached the coaches" by observing coaching sessions and providing support to the new coaches as they implemented the PBC framework within their agency.

Safety PIN evaluation showed significant improvement in all areas of support to reduce infant mortality in 9 counties.



## Additional Highlighted Projects

### Research to Practice in Early Childhood Programs

Major gaps exist between research and practice within early childhood programs. A key function of the Early Childhood Center (ECC) is bridging those gaps through evidence-based practices. This year, the ECC promoted the implementation of two such practices: inclusive special education services and the use of the Pyramid Model. To promote inclusive special education services, Center staff worked with the Indiana Department of Education to support school districts interested in providing high quality special education services to children with disabilities within regular classrooms. To promote the use of the Pyramid Model, staff worked with a local Head Start program to adopt the Model's positive behavior support strategies addressing children's challenging behavior through traditional professional development and applying the evidence-based Practice-Based Coaching model.

### One Community One Family Safety PIN

In an effort to reduce infant mortality rates and increase birth outcomes, Indiana's State Department of Health created Safety PIN (Protecting Indiana's Newborns), a project designed to support new and pregnant mothers with substance misuse to identify and access services. The Center for Collaborative Systems Change (CCSC) partnered with One Community One Family to evaluate their project supporting families in nine Southeastern counties. By projects end, 88 caregivers participated in care coordination, with 76% of families successfully meeting identified goals. Families had considerable needs when starting the care coordination program including transportation support, community connections, healthcare management, and substance use issues. The majority of participants showed statistically significant improvements (decreased needs) in all areas of support.

### Program Evaluation and the Early Childhood Center

Ongoing evaluation is critical to any program's success. The Early Childhood Center (ECC) has initiated two new evaluation efforts. First, the Center is working with the Indiana Department of Education to identify and document model school districts providing high quality inclusive early education services for a majority of their preschoolers with disabilities. This effort has included analyses of child count/assessment data and interviews and classroom observations that document implementation of evidence-based inclusive practices. Second, ECC is working with the Office of Early Childhood and Out of School Care to conduct a performance evaluation documenting the implementation and quality of 15 projects funded through Indiana's federally-funded Preschool Development Grant (PDG). ECC staff have worked with multiple PDG vendors to develop, and now implement, evaluation plans that document progress and assess the soundness of the vendors' efforts.

### Implementation Strategies and Practice-Based Coaching

Integrating Practice-Based Coaching (PBC) into the Early Childhood Center's (ECC) professional development efforts requires frequent and individualized contact, making it difficult to implement with fidelity due to practical challenges such as long distances and classroom or home visiting logistics not always being conducive to observation. ECC staff have adopted several technologies to bridge these space and time obstacles. Rather than spending several hours in a car to conduct a PBC session, staff and participating professionals use: their smartphones and apps to record video classroom or home visiting sessions, specialized software to easily upload and evaluate the video sessions, and video conferencing tools to conduct virtual coaching sessions.

Where the capacity of educational systems and universally designed services meet the needs of all students.



# School-Age

## Educating the Whole Child Summit

Since 2017, the Indiana School Mental Health Initiative (ISMHI) at the Indiana Institute, has provided training and resources to school personnel focusing on the social, emotional, behavioral, and mental health needs of Indiana's students. ISMHI encourages a local Systems of Care where schools collaborate with local community stakeholders including youth, agency partners, and families, to collectively define challenges and provide relevant options around prevention, intervention, and service options.

In February of this year, over 500 school administrators, staff, and school-based community health providers convened in Bloomington to attend a two-day Educating the Whole Child Summit addressing issues pertaining to school mental health. A collaborative between ISMHI, the Indiana Department of Education (IDOE), and the Indiana Division of Mental Health and Addictions (DMHA), the Summit provided an opportunity for school personnel to come together to share information on how districts and community partners have built capacity to address the development of the whole child within existing school framework and improvement plans.

State superintendent of public instruction, Dr. Jennifer McCormick, was a featured presenter and addressed the need for Indiana's schools to further promote and develop effective practices and professional development opportunities to enhance district mental health initiatives. "There is perhaps no greater challenge facing our schools than addressing the social, emotional, behavioral and mental wellness needs of our students," said Cathy Pratt, director of the Institute's Indiana School Mental Health Initiative. "Too often, we look at supports and services in a fragmented manner instead of addressing the needs of the whole child. With this summit, the goal of the Indiana School Mental Health Initiative is that districts will come as teams and leave with plans to create sustainable change in how they support the needs of today's students."

Next steps for Indiana with support from ISMHI include implementing a Multi-Tiered System of Support (MTSS) allowing for integration of work across departments and initiatives as well as identifying next actionable steps to maintain and advance systemic systems change in order to educate the whole child.

ISMHI expands Bring Change to Mind Clubs from 10 Indianapolis-based clubs to 100 statewide.



## Additional Highlighted Projects

### Evaluation of Elkhart County Systems of Care Expansion Grant

Elkhart County in Indiana was awarded a U.S. Substance Abuse and Mental Health Services grant to expand the county's System of Care (SOC) through strategic infrastructure expansion and development of services to youth 0-17 with significant mental health challenges. The Center for Collaborative Systems Change (CCSC) is conducting an external evaluation of SOC expansion and services. Using a community-based participatory approach, CCSC is responsible for the collection and reporting of all grant performance measures that capitalize on existing resources, while building capacity for sustained project evaluation. Multiple data sources are integrated into the study design to explore change over time in service outcomes, return on investment of the SOC as it relates to hospital, residential, and juvenile placement, challenges and achievements of interagency collaboration, and caregiver and youth perceptions of the effectiveness of SOC.

### Improving Students Outcomes through Effective Educators

Building on significant state educational reforms in Indiana in critical areas of culturally responsive classrooms and supporting teacher and building administrator effectiveness, the Center on Education and Lifelong Learning (CELL) works to improve educational outcomes for students with and without disabilities through the Indiana Center on Teacher Quality (ICTQ). ICTQ staff work with six Indiana school districts to increase the number of high-quality teachers by providing job-embedded professional development. The project also works to increase the number of students with disabilities who have access to high quality teachers through improvements in recruitment and retention along with supporting school transitions and post-school student outcomes by aligning policies and practices of key educational stakeholders serving students with disabilities.

### Study on Inclusive Classroom Placement/Higher Academic Outcomes

In a study to determine the impact of inclusion on student academic outcomes, researchers at the Center on Education and Lifelong Learning (CELL) found that Indiana students with disabilities included in general education classrooms do significantly better on Indiana state assessments than their peers placed in separate special education classrooms.

The study investigated the academic outcomes (Indiana State Test of Educational Progress ELA and Math scores) of a cohort of special education students placed in high, mixed and low inclusion settings. Students were followed from the third through the eighth grade. Study findings concluded:

Students with disabilities who spend all of their time in a general education inclusive classroom do significantly better in both reading and math assessment than their peers placed in separate special education classrooms; students with placements classified as "high inclusion" scored better on ELA and Math for all analyses; and of the 40 analyses, 95% of them favored high-inclusion settings for special education students which was statistically significant.

### Bring Change to Mind Clubs

Indiana's School Mental Health Initiative (ISMHI) works with school districts and community partners to build capacity around the social, emotional, behavioral, mental health of Indiana's school children and youth. This year, ISMHI partnered with Bring Change to Mind Clubs (BC2M) out of California to begin 10 clubs in the Indianapolis area. BC2M programs give teens a platform to raise awareness around mental health and are research-based to ensure efficacy. Due to program success, state funding was obtained to create up to 100 more clubs statewide. Funding will also support a BC2M staff member to build a sustainable program, and provide support to hold regional summits.

Where access is improved and expanded to provide opportunities for competitive integrated employment and community living.



# Adulthood

## Family Employment Awareness Training

A new focus of the Center on Community Living and Careers (CCLC) is to ensure that Hoosiers with disabilities and their families have access to the information they need to guide their education-to-employment journey. To this end, the Center supports family education on what to expect to support a student's transition to adult services and life beyond high school.

Ushering in a new initiative this year, CCLC is partnering with IN\*SOURCE, Indiana's parent training and information center for families with special needs, to deliver nine Family Employment Awareness Trainings (FEAT) over the next three years. Indiana will be the fourth state to introduce FEAT. Research has shown that families are often unaware of many of the programs and services available to them that could help their student live a more productive, supported, successful and inclusive life. Funded by Indiana's AWS Foundation, FEAT is designed to develop high expectations for competitive employment and increase knowledge about employment resources for youth, ages 14-22 years, who have a variety of support needs.

CCLC is working closely with IN\*SOURCE to deliver the nine FEAT workshops and engage with families across the northeastern region of Indiana. Each workshop includes a two-day intensive training as well as individual and group follow-up and support. The FEAT curriculum and supplementary resources address employment; education and training after high school; transition to adult health care; support resources for employees and employers; anti-discrimination laws; self-advocacy; funding; services; benefits; and programs available at the local, state, and federal levels.

Finding out what's worked for other families is key to building trust. While attending FEAT workshops, families are able to build high expectations for employment as they meet with local employers and hear the stories of individuals with disabilities who have left school, worked with service providers, interviewed for jobs, and are now earning real wages. Expectations and knowledge are the first steps on the road to action. FEAT is the roadmap.

CCLC led self-employment initiative provides information and support to those with disabilities and their families as they learn about, and consider, self-employment.



## Additional Highlighted Projects

### Day and Employment Services Outcomes System (DESOS) Report

How do working-age adults with disabilities spend their day in Indiana? What types of work are they doing? What outcomes are they achieving related to employment, specifically wages earned and hours worked? These and other questions related to people with disabilities who are receiving supports from Indiana's adult services providers are reported in the Day and Employment Services Outcomes Systems Report (DESOS), a statistical documentation of the types of work or alternatives to work people are engaged in throughout Indiana. DESOS, compiled by the Indiana Institute on Disability and Community for the Division of Disability and Rehabilitative Services and the state's Family and Social Services Administration, aggregated data for 10,843 individuals receiving day and employment services in 2018. Seventy-one Indiana programs participated. Report outcomes indicate that there continues to be a steady increase in non-employment programs in Indiana at 31% over individual job placements at 20%.

### Self-Employment

Innovation and technology have opened new doors to self-employment for people with disabilities. However, self-employment is challenging and often requires additional support. In partnership with Indiana's Governor's Council for People with Disabilities and an advisory group of self-advocates, the Center on Community Living and Careers (CCLC) developed a self-employment initiative providing information and support to those with disabilities and their families as they learn about, and consider, self-employment. Introductory workshops around the state help participants determine if self-employment is an option. Additionally, more intensive two-day trainings offer new entrepreneurs and their families ongoing technical training and support to access resources as well as key community partners to help them overcome barriers to self-employment.

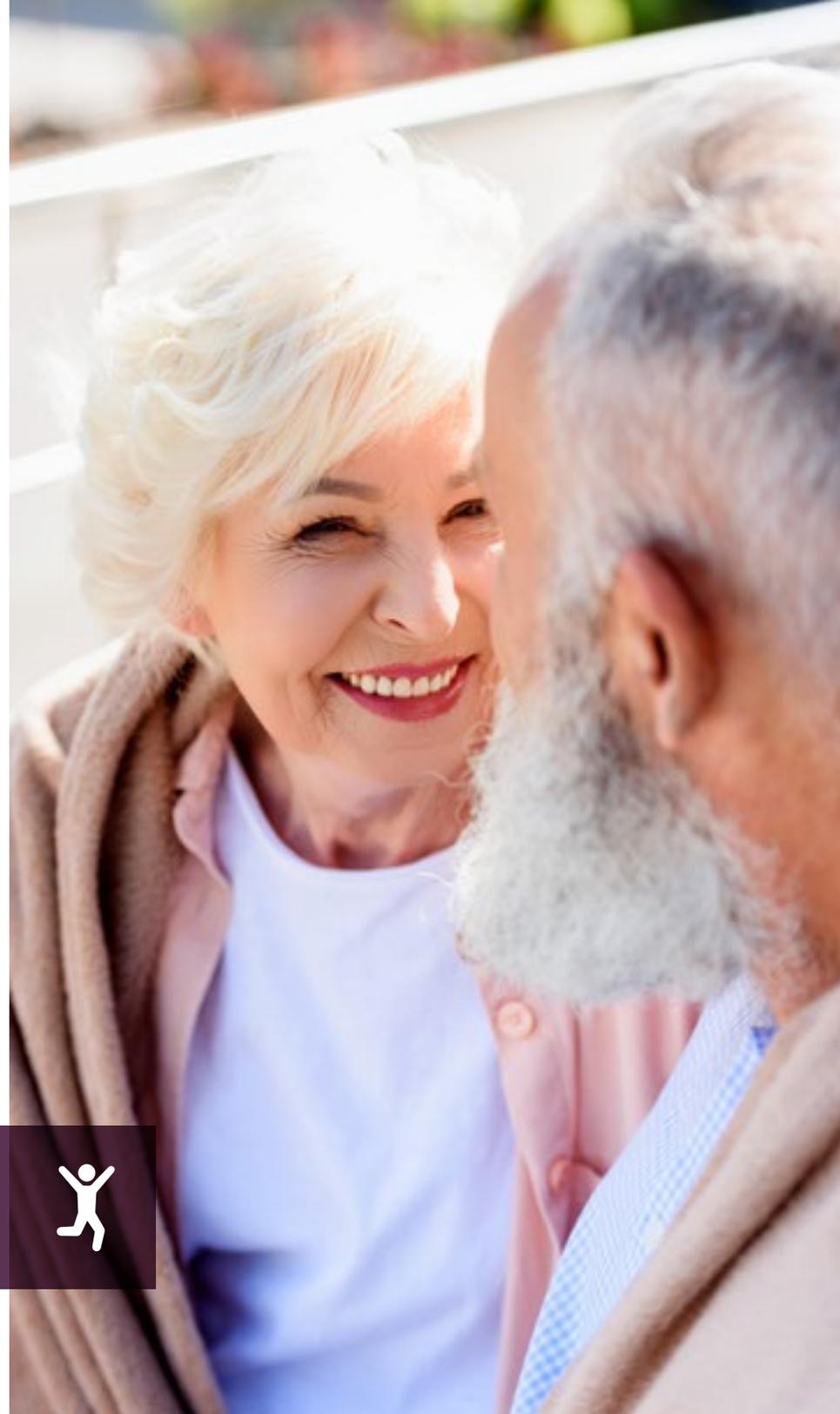
### Improving Sexual Health Literacy and Advocacy Skills Benefits Information Network

Improving sexual health for people with disabilities, especially for those with Intellectual and Developmental Disabilities (I/DD), requires a system change approach because it necessitates significant changes in values, knowledge, and practices of stakeholders in health care, disability services, and families. The Center for Health Equity (CHE), in conjunction with the Indiana Governor's Council for People with Disabilities, aims to improve health and well-being of Hoosiers with disabilities by enhancing sexual health literacy and advocacy skills for adult women with IDD and their partners. Through the development of evidence-based sexual health education, project outcomes will promote healthy lifestyles and illness prevention related to sexual health. Additionally, this project identifies and addresses barriers to women's health care including access, screenings, health literacy, and sexual abuse/exploitation prevention.

### Professional Development

The Center on Community Living and Careers (CCLC) works with Indiana professionals who are teaching in the classroom, counseling at an area Vocational Rehabilitation office, or coaching on a job site. Every year, hundreds of these specialists learn regulations, strategies, and essential knowledge through CCLC trainings funded by the Indiana Department of Education or Indiana Vocational Rehabilitation Services (VR). Professional development trainings include those for teachers on how to create measurable annual IEP goals; for employment providers needing information on state and federal benefits; for VR counselors advising job seekers; for new employment specialists assisting job seekers; for VR managers and community employment service providers working to build teams; and for employment consultants seeking beyond-the-basics trainings in job development and customized employment.

Where individuals participate in all facets of community life and have choice and control over their health and independence.



# Aging

## Living Well

Promoting independence, community integration, and access to quality non-paid and paid community supports and services is the focus of a new Indiana Institute on Disability and Community initiative. In early winter, 2019, the Indiana Division of Disability and Rehabilitative Services (DDRS) contracted with the Indiana Institute to evaluate Indiana's current system for monitoring the safety, health, and well-being of individuals with intellectual and developmental disabilities (I/DD). The Indiana Institute's evaluation work will provide support to guide project management and logistics for project related activities as well as content expertise in the design, implementation, and evaluation of the community monitoring approach.

The Living Well project design engages self-advocates, families, and key stakeholders to ensure full involvement in the development of practices, policies, and procedures to improve Home and Community-Based Services (HCBS). Through these collaboratives, the project aims to develop and implement an improved process for analyzing data from HCBS providers to influence practices, policies, and procedures for increasing the quality of, and access to, services and reduce risk factors for abuse, neglect, and exploitation. Living Well utilizes the LifeCourse framework, developed at the Institute for Human Development, University of Missouri – Kansas City, to increase the capacity and competency of the workforce serving those with I/DD by expanding person-centered planning principals and provides for waiver service improvements and leadership opportunities between DDRS and self-advocates, families, and stakeholders. Five stakeholder meetings have been held to date utilizing the LifeCourse framework to develop and prioritize outcomes.

Indiana Institute Library offers more than 5,000 books, kits, and DVDs that are available to borrow by anyone in Indiana.



## Additional Highlighted Projects

### Guardianship and Supported Decision Making

In April of 2019, the Indiana legislature passed Senate Enrolled Act (SEA) 380, legislation that prioritizes alternatives to guardianship. Indiana is the eighth state to enact legislation that requires consideration of Less Restrictive Alternatives (LRA) to guardianship and recognizes Supported Decision-Making Agreements. In winter, 2019, the Indiana Institute conducted a state-wide survey to understand guardians' knowledge and practices around less restrictive alternatives to guardianship and to make comparisons among family guardians and those in professional guardianship roles. A total of 237 people participated in the survey including 167 family members and 70 professionals. Comparisons between guardians who are family members and professionals found differences across a number of areas including personal and professional characteristics, practice behaviors, and knowledge. Nine recommendations to inform policymakers and professionals were made and include training on Less Restrictive Alternatives to guardianship, the creation of a resource and technical assistance center, and a recommendation that oversight and regulation occur ensuring the rights of individuals under guardianship and/or supported decision-making agreements are maintained.

### Library Resources on Disability

Hoosiers with disabilities, their families, and those who work with and for them need access to appropriate, quality information and resources. The Library at the Indiana Institute on Disability and Community offers more than 5,000 books, kits, and DVDs that are available to borrow by anyone in Indiana. Library materials cover issues impacting the lives of people with disabilities from birth through the aging process, and information is available on topics such as diagnosis, daily living, assistive technology, disability rights, education, employment, community living, early intervention, child care and a special collection of standardized speech/language pathology assessments.

### Oral Health for Hoosiers with Disabilities

In a report by the Institute of Medicine (2011), "vulnerable and underserved populations, including people with special health care needs, have great disparities in access to quality oral health care." "People with disabilities have greater difficulty accessing ongoing care" (Health Resources and Services Administration, 2014). The Indiana Governor's Council for People with Disabilities contracted with the Center for Health Equity (CHE) to collect comprehensive data about the oral health needs of Hoosiers with disabilities as well as the needs of dentists in Indiana. The project employs key informant interviews and electronic surveys to identify oral health needs and experiences in dental health care access. A brief about practice and policy recommendations to improve access to dental and oral care services will also be developed.

### ADA-Indiana

Since 1991, ADA-Indiana has served as a centralized, statewide resource for individuals interested in promoting the implementation of the Americans with Disabilities Act (ADA). As part of the work within the Center for Health Equity (CHE), ADA-Indiana provides support to individuals, organizations, and local communities. Through ADA-Indiana's Coros ADA Community Grants program, four grants to local community organizations to address local ADA issues were awarded. Additional funding and support from ADA-Indiana included three workshops on the employment provisions of the ADA reaching 186 individuals; an Employment First and ADA workshop series reaching 83 participants; and two trainings focused on the expansion of transportation and mobility options for people with disabilities and older adults reaching 80 participants. Other activities included intake of over 180 requests for technical assistance by individuals and organizations and resources disseminated via conference exhibitions, a website, a monthly newsletter, and social media.

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