YEAR IN REVIEW

a look back
at 2019
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FROM THE DIRECTOR

Dear Friends and Colleagues,

I am excited to present the 2019 Annual Report for the UMKC Institute for Human Development (UMKC IHD). I am particularly proud of the accomplishments highlighted here, as this has been a year of tremendous growth and change. In total, we hired 15 new staff whose areas of expertise range from early childhood to online education to bio-statistics to individual advocacy. On top of this, 10 longer-term staff moved into new positions and assumed new responsibilities. This includes my own appointment as Director. It is truly an exciting time for all of us at UMKC IHD.

Part of the change experienced at UMKC IHD is due to the retirement of some of our treasured, longtime leaders. Dr. Carl F. Calkins served as founding Director of the Institute for 41 years. It is impossible to quantify the number of lives he positively impacted through his leadership, mine included. Undoubtedly, the state of Missouri is a better place for people with developmental disabilities because of Carl's work. Dr. Kathy Fuger, who built the early childhood program at UMKC IHD, also retired this past year. We will miss the insightful and positive influence she had on all of our work. Tom McVeigh chose to retire in 2019 after a long and distinguished career. Tom served as Associate Director for Program Development and had a hand in every grant and contract UMKC IHD wrote over the past decade. We owe him a great debt of gratitude for helping us secure funding for our mission-driven work during that time. Lastly, Vim Horn retired in January of 2020. Vim has been at UMKC IHD for more than 30 years, serving as Senior Associate Director for most of that time. He has touched many lives in our state, leaving individuals and systems in Missouri better through his work. Many thanks to each of these leaders! We will miss them and wish them the best as they enter new chapters of their lives.

In spite of all this change, we accomplished much. We highlight many of those accomplishments in the pages that follow. As you will see, this includes helping individuals and families flourish, equipping professionals and students to be agents of change, building community capacity, and providing research and evaluation expertise to our state. Each of these accomplishments is rooted in strong, community-based partnerships. We believe that, through partnership, we will create long-lasting social change resulting in full inclusion of people with developmental disabilities.

Thank you for your support and partnership. We look forward to continuing to work with you in the coming years to achieve a vision of full inclusion for people with disabilities and their families.

Sincerely,

George S. Gotto IV, Ph.D.
Our Story
The UMKC Institute for Human Development (UMKC IHD) began in the 1970’s as the Institute for Community Studies, establishing Missouri’s University Center for Excellence in Developmental Disabilities (UCEDD) in 1977. Close to a decade later, the name evolved to its present form, but the overall purpose remained constant: identifying and addressing individual, family and community needs with a focus on building long-term capacity.

UMKC IHD has now offered more than four decades of sustained leadership and support for the university’s urban-serving mission. We work with a wide variety of partners across all levels - local, state, regional, and national – tackling persistent challenges people and families face throughout the life span, from infancy to late adulthood. We focus on community inclusion and social belonging for all, striving to improve overall quality of life.

Our Relationships
As a center of the University of Missouri-Kansas City, UMKC IHD reports to the Office of the Provost and serves as a bridge between the university and community. Through our engagement efforts, we provide an inter-disciplinary approach to solving problems through research, education, training, and public service.

Our Mission
We build partnerships that lead to effective social change through research, training, community development, and information sharing.

As a University Center for Excellence in Developmental Disabilities, we work to promote self-determined lives for people with disabilities.

As an institute within an urban research university, we work to promote access to opportunities and resources for unserved and underserved populations.

Our Vision
We envision a world where all people live, work and play in their chosen communities throughout their life course.
Institute for Human Development

Helps Individuals and Families Flourish

Equips Professionals and Students to be Agents of Change

Builds Community Capacity

Partners for Progress in Organizations and Systems

Provides Research and Evaluation Expertise
OUR 42nd YEAR

5,315
Individuals received training and continuing education

8
Mass media outlets trained in People First Language

7
Additional dollars leveraged for every $1 of core funding

1,5553
Professionals and family members trained through MOF2F

1,066
Individuals participated in research and evaluation conducted by UMKC IHD

12
Active collaborations built or sustained with other UCEDDs

287
Products disseminated

706
Hours of technical assistance provided
The SOAR conference drew over 300 people with disabilities, family members, and professionals from Missouri, Iowa, Kansas, and Nebraska to the first-ever Midwest leadership and advocacy event.

Helping Individuals and Families Flourish

UMKC IHD helps individuals with disabilities and families who want to learn and expand their own capacity. We provide personal and organizational development opportunities with a special focus on building leadership skills through projects, programs and events that offer direct instruction, connections to others, or technical support.

People First of Missouri & SOAR Conference

UMKC IHD provides ongoing organizational and technical support to People First of Missouri (PFMO), a statewide self-advocacy organization that was formed and is run by people with developmental disabilities. PFMO promotes equality for people with disabilities, so they can live the lives they want in the community. In 2019, UMKC IHD increased its level of dedicated support by adding a new staff member, Candace Cunningham, as PFMO Coordinator. She is also a self-advocate.

May 31-June 2, PFMO partnered with three other state self-advocacy organizations (Kansas, Nebraska and Iowa) to welcome over 220 self-advocates, family members, and allies to a first-ever Midwest regional conference. PFMO was proud to host the “Seeking Opportunities for an Advocacy Revolution” (SOAR) Conference in Independence, Missouri. The event offered networking, learning and fun. Speakers included national disability leader and self-advocate, Ollie Cantos; MMA fighter and self-advocate, Garrett Holeve; comedian and self-advocate, Michael Beers; and leadership expert Ed O’Malley. There were 10 breakout sessions and exhibit tables with information from the four states.

Lead by: Vim Horn, MPA
Funded by: MODDC

“People with disabilities can find their voice by becoming active in self-advocacy organizations.”

Candace Cunningham, PFMO Coordinator
Missouri Family To Family

Almost 30 years ago, UMKC IHD established a resource center committed to providing peer-to-peer support for individuals with disabilities, their parents, and other family members. Known as Missouri Family to Family (MOF2F) since 2008, it has grown and expanded over time and is one of only four Family to Family programs in the nation housed within a UCEDD.

In 2019, MOF2F focused on helping people access local, community-based, and universally available resources. It provided information to help families meet basic needs, such as access to food and disability-aware childcare options.

MOF2F also helped families discover solutions to more complex needs, like exploring creative employment options and new approaches to concerns related to aging.

MOF2F received a 200% increase in referrals in 2019 related to changes in state funding streams and service options. The program supports families during critical moments, such as initial diagnosis, educational adjustments, and life transitions into adulthood and employment. MOF2F also recently updated and relaunched its Peer-to-Peer Mentor program.

Lead by: Georgia Mueller, MS
Funded by: MODDC, MODMH, & HRSA

ACED Adult Education Program

UMKC IHD’s Adult Continuing Education (ACED) program offers adults with developmental disabilities opportunities to attend non-credit classes in university settings. ACED encourages adult students to achieve individual goals by participating in life and skills enrichment classes in an educational and social environment.

ACED recently expanded its services beyond Jackson County, Missouri, to include Clay and Platte counties, offering 72 classes at four sites – UMKC, Avila University, Graceland University, and a new Northland location.

Popular classes included culture (Year of the Dragon), science (Electrified!), cooking (YouTube Tasty), language (American Sign Language) and planning for the future (Tomorrowland). Each session offers new opportunities to learn through creative classes planned by the ACED team.

Lead by: Nancy Carter, M.Ed.
Funded by: EITAS, CC DDRB, & PCBS

SARTAC Fellowships

The national Self Advocacy Resource and Technical Assistance Center (SARTAC) strengthens the self-advocacy movement by assisting state and local groups across the country, serving as an online clearinghouse for information about the history of self-advocacy, providing resources and training in best practices, and offering the SARTAC Fellowship.

UMKC IHD coordinates the SARTAC Fellowship, which is a one-year, independent leadership or policy-related project created and completed by a self-advocate with the support of a host organization. Each year, SARTAC awards six Fellowships through a national, competitive application process. During 2019, the third class of SARTAC Fellows worked on projects related to transportation access, improvement of interaction with law enforcement, expansion of supported decision-making, youth engagement in the movement, sustainability planning for state self-advocacy organizations, and the school to prison pipeline for students of color with disabilities. SARTAC awards Fellows $5,000 to complete their projects and provides ongoing support throughout the year.

Lead by: Danielle Underwood, BS
Funded by: ACL
Over 400 people from 33 states converged in Kansas City, Missouri, for the 3rd annual Charting the LifeCourse Showcase in May. At the event, UMKC IHD launched the Charting the LifeCourse Nexus, a central hub for national collaboration.

Equipping Professionals and Students to be Agents of Change

UMKC IHD equips students and professionals to serve individuals with disabilities, families, and the larger community by providing a framework and tools to understand and respond to the needs of all people. We lead by providing insight, inspiration, and instruction in order to build a better world for everyone.

Charting the LifeCourse Nexus & Showcase

Many families and individuals with disabilities need support to develop a vision for a “good life.” It can be overwhelming to think of everything to know, do, and plan in order to achieve the lives they want to live. The Charting the LifeCourse™ (CtLC) framework and tools grew to meet this critical need with the input of many families and individuals, inspiring a national conversation about person-centered thinking in the process.

In 2019, UMKC IHD launched the LifeCourse Nexus™ to provide centralized support for the development and spread of ideas, collaboration, and nationwide transformation surrounding the framework. The Nexus links people and organizations to the user-friendly Charting the LifeCourse tools and resources, fostering creative exploration of their use through training and technical assistance.

In May 2019, the third annual CtLC Showcase drew over 400 self-advocates, family members and professionals to Kansas City, Missouri, to share CtLC innovations happening in 33 states. The event provided opportunities to discover, share, and plan implementation of Promising Practices to support “good lives” identified by individuals and their families. The next national Showcase will be April 29-30, 2020.

Lead by: Sheli Reynolds, Ph.D.
Funded by: Federal, State and Local Contracts
Civic Engagement

Madam President Camp is a non-residential, one-week, inclusive summer camp that teaches middle school girls the foundational skills needed for leadership and civic engagement. The camp asks each girl to develop a goal based on her own interests, helps her develop a campaign, and gives her tools to support that goal. This includes public speaking instruction and an adult mentor.

In 2019, UMKC IHD offered the program to 26 girls. Participants were 12% Black/African American, 15% Latinx, 15% Asian/Pacific Islander, and 58% White. Three girls came from English-as-a-Second-Language households. Four of the participants had a developmental disability.

Lead by: Julie Warm, Ph.D.
Funded by: Tuition

LEND - Tips4Kids

The Leadership Education in Neurodevelopmental and Related Disabilities (LEND) training program provides intensive training for graduate students and post-doctoral fellows in fields related to neurodevelopmental disabilities. One of 52 state and U.S. territory-based programs of its kind, Missouri’s LEND program is a partnership with the University of Missouri’s Thompson Center on Autism and Neurodevelopmental Disorders. LEND produces interdisciplinary leaders in health care trained to provide family-centered evaluation and assessment services to children with special health care needs.

In 2019, 29 LEND program trainees participated from the disciplines of psychology, speech/language pathology, occupational therapy, physical therapy, social work, special education, and applied behavioral analysis. Two family advocates and two self-advocates also participated in the program. In addition, UMKC IHD also makes select presentations from the LEND program available online for continuing education at no cost. These were accessed by 25 professionals and family members throughout the state in 2019.

Lead by: Connie Brooks, Ph.D.
Funded by: HRSA

Interdisciplinary Studies Program

UMKC IHD collaborates with the UMKC School of Graduate Studies to offer the Interdisciplinary Leadership in Disability Studies Certificate (ILDS). Through the program, those who have already earned degrees but want to learn more about disability as an academic discipline can gain advanced training in the emerging, interdisciplinary field of disability studies. The certificate may be used to complement a master’s, professional, or doctorate degree, or on its own. Students in the program consider disability from historic, legal, societal, and philosophical perspectives. The program is designed for a variety of students who would like additional skills to work alongside or support people with disabilities. In 2019, ILDS conducted market analysis to look for expanded opportunities for students, determine the needs of potential employers, and realign the curriculum based on those discoveries.

Lead by: Julie Warm, Ph.D.
Funded by: Tuition

Julie Warm
Associate Director, Civic Engagement

UMKC IHD prepares future leaders to engage with their communities for positive change.
Jane St. John facilitates round table discussion at the first meeting of the Missouri Consortium on Supported Decision-Making (SDM), formed in 2019. The Consortium is uniting partners across Missouri to increase community capacity through increased understanding and use of SDM strategies.

Building Community Capacity

UMKC IHD recognizes the importance of strong communities. We reach across cultures and varied experiences to build connections and capacity. We foster positive and effective social change by strengthening networks of people and equipping them for leadership.

Supported Decision-Making in Missouri

In response to Missouri guardianship reform enacted in 2018, UMKC IHD identified a critical need for an organized statewide effort to increase understanding and awareness of Supported Decision-Making (SDM). SDM is an alternative model to guardianship that allows people with disabilities to keep their civil rights intact and increase their decision-making capacity. People who use SDM identify trusted advisers, such as friends, family, or professionals, to serve as supporters. The supporters help the person with a disability to recognize, make, and communicate their own choices.

In 2019, UMKC IHD convened the Missouri SDM Consortium to move forward on momentum generated through a Symposium held the previous year. Through the SDM Consortium, UMKC IHD is bringing together a diverse group of stakeholders to develop work groups and action plans to advance the adoption of SDM practices in the state by the disability and aging communities. This year, UMKC IHD received a one year federally funded planning grant to support the effort.

Lead by: Jane St. John, BA
Funded by: ACL
Lay Educational Advocacy Project

Families and individuals navigating the special education system often feel lost, alone and outnumbered by school professionals when it comes to being able to make their needs and wants known. Students with disabilities and their families need access to knowledge, training and support to help them navigate special education services. However, like many states, Missouri has a shortage of trained professionals who can provide these vital resources. This leads to the reduced ability of families to advocate for their children in the school environment.

The Lay Educational Advocacy Project (LEAP) equips those who are interested in learning the basics of Special Education law with skills to work alongside and advocate for students with disabilities and their families. LEAP is also creating an active network of certified “Lay Educational Advocates” and knowledgeable organizations to support those who complete the program.

Lead by: Sheli Reynolds, Ph.D.
Funded by: MODDC

Urban Mission

UMKC IHD’s Urban Mission program is an example of intentional partnership with MU Extension. Its overall goal is to work collaboratively with the greater Kansas City community to address issues of equity, inclusion, and youth empowerment. In 2019, the Urban Mission team offered action research training workshops to help community organizations collect and analyze data. By understanding the needs of their target audiences, organizations can better serve the community in ways that also align with their internal missions.

Additionally, the UMKC IHD team offered Youth Participatory Action Research (YPAR) training to area youth. This training helps young people identify issues they face in their particular communities and equip them with the tools to investigate the problem and find program and policy solutions. YPAR has been shown to improve positive youth outcomes such as self-efficacy.

Lead by: George Gotto, Ph.D.
Funded by: MU Extension

Alianzas

A joint program of UMKC IHD and University of Missouri Extension, Alianzas (Alliances) builds intercultural communication between MU Extension, Latinx residents, and the larger community. It provides intercultural competency training and professional development to support Extension Specialists to increase inclusion of Latinx in their educational outreach. Alianzas also assists organizations and individuals who want to reach out to Latinx in their communities.

This year, Alianzas has provided training on Latinx cultural values to hundreds of educators and community members across Missouri, increasing cultural competency skills and MU Extension specialists’ confidence in reaching out to Latinx families and individuals. Alianzas currently targets its efforts on 27 Missouri counties where larger numbers of Latinx individuals reside. It has also begun creating bridges and connecting with Latinx student outreach initiatives taking place on the four campuses of the University of Missouri system in Kansas City, Columbia, St. Louis, and Rolla. It continues to support binational health week efforts across the state.

Lead by: Gerardo Martinez, MBA
Funded by: MU Extension

Through Alianzas and other programs, UMKC IHD builds capacity among Latinx and other underserved communities.

Gerardo Martinez
Alianzas Director
The National Community of Practice (CoP) for Supporting Families welcomed five new states in 2019, bringing the total collaboration to 19 states. Representatives of new member states and the CoP national team are pictured above.

Partnering for Progress in Organizations and Systems

UMKC IHD participates in systems change by working in close partnership with influential thought leaders and organizations at local, state, and national levels. We use our platform to advocate for person-centered thinking and systems.

National Community of Practice for Supporting Families

UMKC IHD, in partnership with the National Association of State Directors of Developmental Disabilities Services (NASDDDS), facilitates the National Community of Practice (CoP) for Supporting Families. Formed in 2012, the Administration for Community Living (formerly the Administration on Developmental Disabilities) funded five states and a mentor state to work together to build capacity across and within their states. Their goal was to create policies, practices and systems to better support families that include a member with an intellectual or developmental disability in all life stages. In 2019, the CoP grew to include 19 member states and is sustained through state membership fees rather than national funding. Utilizing the Charting the LifeCourse™ framework as its guiding principles, the LifeCourse Nexus and NASDDDS project teams provide technical assistance and shared learning opportunities to the CoP. Through their participation, member states are implementing innovative organizational and system changes, enhancing person-centered planning, meaningfully engaging self-advocates and families, and redesigning the “front doors” to their disability service systems.

Lead by: Sheli Reynolds, Ph.D.
Funded by: NASDDDS & Participant States
Division of DD Capacity Building & Quality Enhancement

The Missouri Division of Developmental Disabilities (DDD) contracts with UMKC IHD to enhance Missouri DD service system policies, practices, and structures. This partnership provides for the development and implementation of evidence-based person/family-centered and integrated community supports. It also generates ongoing quality improvement strategies that affect people with developmental disabilities, families, professionals, providers, statewide systems, external partners, and communities. UMKC IHD provides process consulting, evaluation, quality improvement support, and technical assistance as needed to DDD around identified priority areas, such as cultural change, support coordination, targeted case management and more.

Lead by: Jenny Turner, MSW
Funded by: MODMH

Missouri Disability & Health Collaborative

In 2019, the Missouri Disability and Health Collaborative (MDHC) focused on training for public health and disability professionals, self-advocates, and family members. Statewide, 122 professionals, 22 people with intellectual disabilities (ID), and three family members attended trainings on Charting the LifeCourse™ tools, accessible cooking materials and recipes, Universal Design strategies, and health disparities facing people with ID. Public health agencies in 17 Missouri counties completed chronic disease action plans using an inclusive community assessment tool for the first time. In year four, UMKC IHD and the Missouri Department of Health and Senior Services will provide intensive technical assistance to these counties to implement their plans using inclusive strategies that will impact the lives of people with ID. The MDHC Advisory Committee continues to cultivate productive partnerships that build new bridges between the public health and disability fields and promote the active participation of people with ID in community health and wellness programs in Missouri.

Lead by: Christy Miller, MHA
Funded by: CDC

Early Childhood Education

UMKC IHD convened the Missouri Early Childhood Workforce Advisory Council in 2019 to examine state systems that support individuals working in childcare, preschool, Head Start, home visiting, and other programs serving young children and their families. The Council reviewed Missouri’s early childhood workforce system including credentials and certification (licensure), a robust professional development registry, and the Missouri/Kansas Core Competencies for Early Childhood Professionals. Members identified several issues impacting the state’s early childhood workforce and drafted nine preliminary recommendations to guide Missouri’s professional development system and identify clear and articulated career advancement pathways. UMKC IHD also assembled a separate higher education task force to work with the Council on specific issues related to higher education programs. The Council is a component of the federal Preschool Development Grant program administered by the Missouri Department of Elementary and Secondary Education.

Lead by: Mike Abel, Ph.D.
Funded by: DESE
Providing Research and Evaluation Expertise

UMKC IHD engages with communities to provide meaningful research and program evaluation that advances knowledge about human development and services. In 2019, UMKC IHD conducted evaluations of the following programs:

Team for Infants Exposed to Substance Abuse

UMKC IHD continues to partner with Children’s Mercy Hospital on the Team for Infants Exposed to Substance Abuse (TIES) Program, which uses a community-based model to address needs of families with young children affected by maternal substance use.

In 2019, TIES validated its Individualized Family Service Plan tool and submitted a peer-reviewed journal manuscript and a national research conference poster. TIES also began conducting quasi-experimental research to establish an “evidence-based” status for the program. UMKC IHD contributed through efforts to validate the primary outcome measure, administer assessments, perform data analysis, and disseminate quarterly findings to the TIES program manager, staff, Advisory Council, and others.

Lead by: Danielle Chiang, Ph.D.
Funded by: HRSA, KDHE, MIECHV, and Children’s Mercy Hospital

Kansas City Healthy Start Initiative of Nurture KC

The Kansas City Healthy Start Initiative with Nurture KC (formally Mother & Child Health Coalition) addresses health disparities in 14 urban ZIP codes in the bi-state Kansas City metro area. Community Health Workers (CHWs) at three sites coordinate comprehensive care for underserved infants, mothers and fathers.

UMKC IHD provides ongoing evaluation for this project as well as training for CHWs on proper use of assessment tools, maintaining the informational database, and monitoring outcomes. UMKC IHD disseminates benchmark data results by providing quarterly evaluation findings and an annual progress report to Nurture KC, its board, the Healthy Start project manager, and all CHWs.

Lead by: Danielle Chiang, Ph.D.
Funded by: Nurture KC & HRSA
Living Well - Model Approaches of HCBS Services

The Missouri Living Well Initiative is a five-year, federally funded project with a big goal: substantially improve quality of life for people with developmental disabilities who receive Home and Community Based Services (HCBS) and keep them free from abuse and neglect. Missouri is one of only five states in the nation to receive the grant award.

In its first project year, UMKC IHD established a statewide network of partners, recruited stakeholders, and began to identify strategies for policy, practice, organizational, systems and communitywide change. In future grant years, Living Well will align community-monitoring systems statewide as well as address capacity building needs. The project utilizes the Charting the LifeCourse™ framework and Ambassador training series to guide the network in this effort.

Lead by: Sheli Reynolds, Ph.D.
Funded by: ACL

Aging Projects - Reducing Disability in Dementia

Through an Administration on Community Living grant, UMKC IHD collaborates with several Kansas City organizations in the Kansas City Collaborative for Dementia Capability. Last year, the Collaborative provided dementia capability training to 202 support professionals and implemented a behavioral management and exercise program (Reducing Disability in Dementia, RDAD) with 77 “dyads.” Dyads include a caregiver plus either an individual with moderate to moderately severe Alzheimer’s disease and related disorders (ADRD) or an individual aging with intellectual and developmental disabilities (IDD) at risk of developing ADRD.

In 2019, UMKC IHD organized the Missouri Summit on Aging with IDD to bring statewide leaders in the fields of Aging and IDD together to identify needs, outline priorities, and explore opportunities for innovation and collaboration to best support individuals aging with IDD.

Lead by: Kelli Barton, Ph.D.
Funded by: ACL

STAHR Program with UMKC School of Medicine

The STAHR Partnership Program increases the number of students from educationally and/or economically disadvantaged backgrounds who are prepared to enter, persist, and graduate from a health sciences degree program at UMKC. The program includes two major components, the STAHR Scholars Program for high school and college students, and the STAHR Ambassador Program for students admitted to the UMKC School of Medicine, pre-dental, pre-pharmacy, pre-health, biology, chemistry, health studies, or other health-related programs.

In 2019, the STAHR Scholars Program launched its first six-week summer program for 46 high school and college students, which offered students supplemental instruction in health science and shadowing experience in medicine, dentistry, pharmacy, and allied health at Truman Medical Center. The STAHR Ambassador Program also held its first-year’s retreat with 95 students and faculty in September 2019. The students participate in the program for one year and receive mentorship and engagement through psychosocial, career development, academic, financial, and research opportunities.

Lead by: George Gotto, Ph.D.
Funded by: HRSA
NOTABLE MOMENTS

TOP ROW (left to right)
Alianzas Latinx Leadership Series graduates pose for a celebratory picture.

UMKC Chancellor C. Mauli Agrawal and Provost Barbara Bichelmeyer visit UMKC IHD.

Sheli Reynolds receives the “Friend of MACDDS” award at its 40th anniversary banquet.

MIDDLE ROW
People First of Missouri elects new statewide officers.

Vim Horn and Tom McVeigh retire after decades of service to UMKC IHD.

Madam President Campers meet with the Mayoral staff of Sly James in City Hall.

BOTTOM ROW
UMKC IHD staff members surprise newly appointed Director George Gotto.

Travis Anderson comments for a KCUR investigative report on the direct support staffing crisis in Missouri.
BUILDING PARTNERSHIPS
FOR EFFECTIVE SOCIAL CHANGE

UMKC IHD Staff and Advisory Leadership Team members, September 2019

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