

Human Development Institute University Lecture Series 2019

Foundational lectures

1. Disability Law

This lecture will provide a brief overview of relevant disability legislation, including the Americans with Disabilities Act, and the Individuals with Disabilities Education Act. These laws have been part of the disability rights movement which includes the independent living movement.

Kathy Sheppard-Jones, Jason Jones

2. Disability Resources in Kentucky

This lecture uses the Kentucky Disability Resource Manual and online searchable Kentucky Disability Guide to provide detail around services and supports that are currently available in the Commonwealth. This lecture could provide information on ABLE accounts, with a particular emphasis on Kentucky's ABLE program, as well as Life Plan of Kentucky, Inc., Kentucky's pooled special needs trust program.

Walt Bower, Kathy Sheppard-Jones, Carolyn Wheeler

3. Disability in Kentucky

This lecture includes a snapshot of disability statistics for the state, an overview of models of disabilities, definitions, and an introduction to the state of the Commonwealth with regard to education, employment, and independent living.

Kathy Sheppard-Jones and Carolyn Wheeler

4. Getting Comfortable with Disability

Are you afraid of saying or doing the wrong thing when interacting with a person with a disability? Do you avoid those interactions because of that fear? Are you missing out on a huge part of the population that could be customers, employees, resources ... friends? Explore the attitudinal barriers faced by people with disabilities in all aspects of life. Hear real life stories that offer examples for each barrier. Join in discussion around etiquette and myths around a variety of disabilities. Get comfortable.

Jason Jones, Christina Bard

5. Transitions to Higher Education and Employment (1 or 2 hours)

Transition represents a critical passage for youth with disabilities. Moving from a system of entitlement of educational services to adult services of eligibility can lead to transitions to the couch instead of the workplace. Kentucky provides a variety of supports and resources aimed at improving transition outcomes, with an emphasis on students with the most significant disabilities.

Kathy Sheppard-Jones

Employment & Community Living

6.Independent Living

For people with disabilities to be fully included in society, principles around universal design and independent living provide the underpinnings of basic rights for inclusion, regardless of level of disability. A physically accessible environment is the foundation for independence. Discussion will focus around resources and Centers for Independent Living.

Kathy Sheppard-Jones, Jason Jones, Christina Bard

7.Stay at Work/Return to Work

Millions of workers leave the workforce each year after experiencing an injury or an illness. This can result in detrimental outcomes to displaced employees, employers, and the economy.

However, stay at work/return to work strategies can help workers maintain their jobs and their way of life. This lecture will provide an overview of national SAW/RTW policy and efforts here in Kentucky.

Kathy Sheppard-Jones

8.Waiver Redesign and Its Impact on Employment First

The waiver redesign presentation is a brief description of Medicaid waivers and the role they can play in helping people with significant disabilities move toward independence. Topics include: What is a waiver? Why did 1915(c) waivers become popular? Average cost of community services vs. facility services; Kentucky's waiver menu; Supported Employment vs. Day Training; Design Challenges; Rate Structure Challenges; and, moving toward Employment First.

Jeff White

9.What is Next: Looking Toward Adulthood and Beyond

This lecture is designed to help learners understand the relationship between the benefits a person receives and their ultimate ability to live as independently as possible, with particular attention paid to the transition from child to adult status. We will work through the three subgroups within the transition age population: Students 14 to 17 years of age, students who are close to their 18th birthday, and students over age 18. As we do this, we will pay close attention to the important topics for each group to move toward independence and maintain eligibility, as well as prepare for future challenges.

Jeff White

10.Unscrambling Myths: The Truth about Work, Wages, and Waivers

The Unscrambling Myths presentation addresses the true impact of wages on benefits and patient liability. This presentation includes a comparison between benefit streams, an analysis of pass-through and how it can benefit recipients, a discussion of programs that help pay medical expenses, an analysis of substantial gainful activity and SSDI work incentives, real life examples of the impact of wages on SSI, a discussion of SSI work incentives, an examination of resource management strategies, examples of the management of patient liability, and a discussion of reporting requirements.

Jeff White

11.The Impact of Employment on Social Security Disability Benefits – How Working and Benefits Work Together

Did you know a person could earn \$1200/month (gross) and still maintain eligibility for Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI)? Did you know a person eligible for SSI and Medicaid could earn over \$25,000/year and still maintain eligibility for Medicaid? This presentation provides factual information on what Social Security allows for a person's SSI or SSDI payment when a beneficiary goes to work. Resources which can be used by the person receiving the benefit, family members, employment service providers and employers are provided, as well as information about ABLE accounts and Special Needs Trusts as ways to save without jeopardizing eligibility for other publicly funded benefits.

Carolyn Wheeler

12.Creating A Safe and Secure Future - Supporting People with Disabilities and Their Allies to Plan for the Future

Since over 70% of North Americans die without a will, it is no surprise that people with disabilities and their allies (family members, supporters, legal representatives) have not made plans for what happens when a key ally or family member dies. This can create a crisis and often very negative life experiences for the person with a disability. This presentation shares four questions that need to be addressed as well as resources for people to use to take action on this important topic.

Carolyn Wheeler

13.Financial Planning Tools for People with Disabilities Who Receive Social Security Disability Benefits and Their Family Members

Most people who receive Social Security Disability Benefits are under the misconception they cannot save for the future. This is not TRUE!!! STABLE Kentucky is Kentucky's ABLE (Achieving A Better Life Experience) program which allows a person whose disability occurred before the age of 26, their family member, friends, etc. to save up to \$15,000/year without jeopardizing the person's Supplemental Security Income eligibility or Medicaid eligibility. Supplemental and Special Needs Trusts allow for more funds to be saved and used for supplemental needs. This presentation will provide an overview of these tools as well as provide resource information.

Carolyn Wheeler

14.Supported Decision Making

Supported decision making is just a way to describe how we all make decisions. It means that people turn to trusted friends, family members, and professions to help them make decision, both large and small. Supported decision making can be used as an alternative to legal guardianship, but can also be used in any person's life.

Laura Butler, Camille Collins-Dean

Considerations for Children with Disabilities

15.Early Childhood: Children with Disabilities, Transitions, Social-Emotional Development

Caroline and Christine present on topics key to early childhood development for children with disabilities, as well as for their families and peers. Topics include tips for transitions within the early childhood years, from early intervention to preschool and from preschool to kindergarten,

from the perspective of children, their families, and teachers. As KY's Ambassador for the Center for Disease Control's "Learn the Signs, Act Early" campaign, Christine presents on the early identification of children with autism and other developmental disabilities so that children and families can access the services and supports they need.

Christine Hausman, Caroline Gooden

Considerations for Families of Persons with Disabilities

16. Parenting a child with a disability

This discussion covers the experiences of parenting a child with Down syndrome from the moment of diagnosis to the first day on the job as an adult. We cover important milestones like rebuilding dreams after a diagnosis, working toward developmental milestones through early intervention, preparing for the first day at school, cultivating healthy sibling relationships, encouraging community and school inclusion, and preparing for work.

Stephanie Meredith

Advocacy

17. Self-Advocacy Panel

Self-advocates will provide an overview of self-advocacy, including the history of self-advocate movements created by people with intellectual disabilities. The presenters will discuss past and current uses of the term "self-advocate" and will describe a variety of activities that can fall under the umbrella term. The presenters will discuss their experience with forming and leading a self-advocacy group for autistic adults and youth and will offer suggestions for others interested in joining or forming a group.

Bev Harp, Autistics United KY (AUK) and Kentuckiana Autistic Spectrum Alliance (KASA) Members

18. Family-Advocacy Panel

Families will provide overview of the importance of advocacy. Personal perspectives will be shared, along with applications of advocacy in health care across the lifespan and across domains. Advocating as a parent can change across the lifespan. For example, a child who is young, nonverbal, and requires full-time, round-the-clock care requires a different kind of advocacy than for an employed and active adult.

Traci Brewer, Jennifer Ulbricht, Stephanie Meredith

19. Community Engagement

This lecture will share and discuss opportunities to collaborate with our community partners. The lecture will discuss identifying community stakeholders, successful relationship building within the community, the staff necessary to carry out the mission of the organization, and lessons learned from developing community partnerships with agencies that are serving children and adults with disabilities and their families.

Walt Bower

20. Allyship

Anyone can be an ally to people with disabilities; the fundamental tools required are thoughtful listening and a willingness to step back and let disabled people lead. This training is designed for professionals, family members, direct support workers, and anyone else who would like to learn

how to better support people with disabilities. The presenters will discuss the meaning of allyship and its importance to people with disabilities and will offer a wide range of interactive scenarios for evaluating efforts and improving allyship skills.

Bev Harp, Tony Lobianco

21.Unconferencing: Using Open Space to Support Conversations about Disability

Since 2012, HDI has been instrumental in bringing participant-driven meetings, called unconferences, to Kentucky residents with disabilities, their family members, and support workers. The unconference format is inherently democratic, providing a space where disabled voices can be centered. Learn how it works and results of our 4 unconferences on sexuality as well as the more recent disability leadership unconference.

Bev Harp, Laura Butler

22.Autistic Self-Advocacy in Kentucky

Did you know that Kentucky has two self-advocacy groups by and for autistic people? Autistics United Kentucky (AUK) and Kentuckiana Autistic Spectrum Alliance (KASA) engage in advocacy, social justice actions, and community events, promoting the rights of all autistic people. We also have a lot of fun! Learn about some of our past, present, and future projects.

Bev Harp, AUK and KASA members

Health

23.Inclusive Health

Individuals with disabilities are 3 times more likely to experience heart disease, stroke, diabetes, and cancer. Kentucky is one of the highest ranked states with a disability rate of 33.2%. This lecture provides an overview of the health disparities experienced by people with disabilities, along with providing insight on strategies for inclusive health through education, empowerment, and cultural competency.

Lindsey Mullis, Megan Jaspersen, Kathy Sheppard-Jones, Danielle Augustin

24.Rural Rehabilitation and Access to Health Care

Challenges in rural health care include lack of physical access to facilities, lack of special equipment, and lack of healthcare provider knowledge in working with individuals with complex needs. Because of this lack of access, many individuals are forced to travel long distances to metropolitan areas for their healthcare, or individuals wait until problems that are easily treated become very advance problems and seek treatment in the local Emergency Department.

Therefore, a lack of access not only impacts the person's quality of life, it also leads to an overall increase in healthcare costs. This lecture will provide an overview of some of the rural disparities and will include opportunities for implementation of solutions in rural healthcare, including results of rural healthcare accessibility surveys in Kentucky.

Christina Bard, Jason Jones, Kathy Sheppard-Jones

25.Health Care Access Dialogue

Informative interview regarding cancer care for persons with disabilities, developed in collaboration with Human Development Institute and Markey Cancer Center staff. The nature of disparities in medical care for adults with disabilities is introduced. Information includes real time information from adults with disabilities, such as helpful attitudes from medical staff, positive

approaches to medical care, patient transfer, and access to medical facilities. Information presented applies to many interactions between medical staff and persons with disabilities. This session can be presented live, or viewed via recording at <https://www.wellness4ky.org/project-cheer-partners-with-markey-cancer-center-to-create-disability-awareness-webinar/>

Morgan Turner, Jason Jones, Lindsey Mullis, Danielle Augustin

26. Universal Design in Health

Learn why it is important to include universal design in health promotion programming and gain insight on how to include strategies that will assist you in reaching the widest possible range of participants. Presentation will provide examples of incorporating universal design in health messaging including print materials and program activities.

Lindsey Mullis, Megan Jaspersen, Morgan Turner, Danielle Augustin, Kathy Sheppard-Jones

27. A Dyad Approach to Inclusive Health

This session will cover the importance of incorporating an inclusive approach into health & wellness programming that highlights successful ways for individuals with varying levels of ability and their networks of support to successfully identify and work towards self-determined health goals. This session will also provide success strategies on partnering together to provide accountability and built-in community support for program participants of all abilities.

Lindsey Mullis, Megan Jaspersen, Morgan Turner

28. Adaptive Wellness Resources and Activities

Recreation refreshes, revitalizes, and improves a person's quality of life. Learn about HDI's Kentucky Recreation Resource Guide and wellness4ky website, which highlights resources around our state that include things like state parks, adaptive recreation programming, sports clubs and teams as well as inclusive activities that can be done anywhere.

Lindsey Mullis, Megan Jaspersen, Morgan Turner, Danielle Augustin

29. Sexuality & Disability

Sexual health and healthy relationships for individuals with disabilities are often overlooked and undervalued. This presentation provides insight and resources into the topic for educators, health providers, and caretakers on sexuality for individuals with disabilities to recognize the importance of sexuality and create a positive environment for improved and safe sexual opportunities. This presentation can be catered to intellectual and developmental disability or physical disability.

Lindsey Mullis, Jason Jones

30. Genetics, Ethics, and the History of Developmental Disabilities/Eugenics

This lecture reviews the history of the modern eugenics movement from the early 20th century to current prenatal testing technologies. Many of these genetic technologies to "control breeding" and eliminate people with "undesirable traits" have emerged at the same time as the deinstitutionalization and subsequent civil rights movements for people with disabilities. Explore ideas about how to ethically approach the schism between genetic testing and the disability rights movement and current efforts toward that goal.

Stephanie Meredith

Assistive Technology and Universal Design

31. Assistive Technology

This session will define assistive technology terminology and practice. We'll discuss categories of AT, and how AT can be applied toward greater independence across the life span. We'll examine AT's usefulness for independent living, employment, community participation, and education.

Christina Bard, Jason Jones

32. Universal Design: Creating Utopia Starts with a Plan

Universal design principles can build environments that are accessible to the broadest array of users. Learn about strategies that maximize usability in physical and virtual environments. We'll examine a variety of applications of universal design at use in the workplace, community, and classroom.

Kathy Sheppard-Jones

33. Universal Design and Learning: Supporting all Learners in Professional Development

The inclusion of all learners, regardless of ability, is essential in training and teaching environments. The goal of this talk is for learners to leave with the skills to begin implementing universal design strategies in their work.

The lecture is intended to give learners an overview of universal design and practical ways to use accessibility practices in the creation of documents.

Objectives include: List reasons why universal design supports all learners; Describe the relationship between accessibility and universal design; Evaluate a document and make recommendations for how the document can be made more accessible; Produce a handout/document free of accessibility errors.

Patti Singleton

34. Taking the Leap: Design and Development of Problem-Based Online Learning

Online learning has become a mainstay in early care and education professional development. This session is for trainers or faculty who need guidance for developing online training, or for anyone who is training online and would like to make content interactive, engaging, and universally designed. Two stages of development will be discussed, as well as turning problems into online learning solutions. Questions and answers will be addressed in real time with the use of your smart phone, tablet, or computer.

Objectives include: Develop a problem-based learning objective; Identify a knowledge, skill, and attitude for your learning objective; Develop an assessment for the knowledge, skill and attitude; Identify universal design for learning strategies

Patti Singleton

35. HDI Research and Educational Opportunities for UK Students

This lecture will further enhance the interdisciplinary training aspect of the Graduate Certificate and the Undergraduate Certificate as more on campus students become involved with HDI projects. The lecture will discuss research opportunities available for students to engage with HDI projects, practicum opportunities available for students, and HDI's family mentor program as a valuable training opportunity for students to learn first-hand from the family's perspective.

Kathy Sheppard-Jones, Walt Bower