

AUCD/AAIDD Joint Webinar

Ethical Issues in Developmental Disability Research

April 19, 2012 1:30 - 3:00 EST

Researchers conducting research with persons with intellectual and developmental disabilities encounter a variety of ethical challenges. These ethical challenges intersect with US federal law that governs the rules and regulations of human subjects research and local review of research through Institutional Review Boards (IRBs). IRBs seek to ensure that research participants' rights and well-being are protected; guiding principles that are shared throughout the world. Since individuals with intellectual and/or developmental disabilities may experience greater vulnerability, researchers need to consider contextually-relevant factors (e.g., consent capacity, risk/benefit ratios) to meet the goals of ethical research. These ethical issues are complex for even the most experienced researchers and IRB members.

In this webinar, **Dr. Katherine (Katie) McDonald**, Assistant Professor of Public Health, Food Studies and Nutrition in the Falk College of Sport and Human Dynamics and a Faculty Fellow at the Burton Blatt Institute at Syracuse University, and **Dora Raymaker**, MS, co-director of the Academic Autistic Spectrum Partnership in Research and Education (AASPIRE) will discuss the core principles and practices governing IRB review, ethical issues in research with individuals with intellectual and/or developmental disabilities, and ideas on how researchers can incorporate disability rights principles into their research with this population.

To register go to:

About the Presenters:



Katherine McDonald, Ph.D.

Katherine (Katie) McDonald, PhD, is an Assistant Professor of Public Health, Food Studies and Nutrition in the Falk College of Sport and Human Dynamics and a Faculty Fellow at the Burton Blatt Institute at Syracuse University. She received her B.S. with Distinction in Human Development and Family Studies with a minor in French from Cornell University and her Ph.D. in Community and Prevention Research

Psychology from the University of Illinois at Chicago. Previously, Dr. McDonald lived in community with individuals with and without intellectual disabilities in a community of L'Arche. Her experience with l'Arche taught her a great deal, and fueled her passion to contribute to improving the quality of life experienced by persons with developmental disabilities. Dr. McDonald's work, research and service use ecological theory and social action approaches to understand and promote the community integration of individuals with disabilities. Her current research includes two core areas of inquiry. **(1) Respectful, Inclusive Research:** Dr. McDonald has several projects involving the empirical study of human research ethics, with an emphasis on the research participation of adults with developmental disabilities. Her long-term goal is to contribute an empirical perspective to respectful, inclusive research practices. **(2) Participatory Action Research Addressing Disparities:** Dr. McDonald also conducts collaborative research with community-based organizations and community members on health, education and employment disparities experienced by individuals with disabilities. Dr. McDonald has served on the Boards of Directors for L'Arche Nehalem, l'Arche Chicago, and the Arc of Multnomah-Clackamas County as well as on two university IRBs. Dr. McDonald received the Stevens-Shapiro Fellowship from the International Association for the Scientific Study of Intellectual Disabilities in 2008 and has been selected to receive the 2012 Early Career Award from the American Association on Intellectual and Developmental Disabilities.

<http://falk.syr.edu/Faculty/McDonaldKatherine.aspx>



Dora Raymaker, M.S.

Dora Raymaker, MS, co-directs the Academic Autistic Spectrum Partnership in Research and Education (AASPIRE, <http://aaspire.org>), a community-campus partnership that conducts research to improve the lives of adults on the autism spectrum. She has served in leadership positions in governmental autism policy groups, such as the Oregon Commission on Autism Spectrum Disorder, and self-advocate organizations including Self-Advocates as Leaders and the Autistic Self Advocacy Network. Her research interests include complex systems, social dynamics, and the impact of community-campus partnerships on science, society, and public policy. She enjoys writing fiction and painting.