

AWARD PROGRAM

AAIDD 138th Annual Meeting

June 23–26, 2014 | Orlando, Florida

Embracing Complexity

Inclusion, Participation, and Citizenship



 **aaidd**

American Association
on Intellectual and
Developmental Disabilities

AAIDD 138th Annual Meeting

June 23–26, 2014 | Orlando, Florida

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2014 AWARDS PROGRAM

2014 AAIDD AWARDS RECIPIENTS

Nikki L. Murdick, PhD, FAAIDD
Chairperson, Awards and Fellowship Committee

Wednesday, June 25, 2014—8:00 am

Sheryl White-Scott, MD.....	Dybwad Humanitarian Award
Julie Lounds Taylor, PhD	Early Career Award
Jan Rosemergy, PhD	Education Award
Claudia Claes, PhD	International Award
Positive Expose: The Spirit of Difference	Media Award
Elise McMillan, JD	Service Award
Dora Raymaker, MS.....	Student Award



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Presidential Award Todd D. Little, PhD

Todd D. Little, PhD is a Professor of Educational Psychology at Texas Tech University (TTU) where, in 2013, he became the founding director of the Institute for Measurement, Methodology, Analysis, and Policy (IMMAP). The IMMAP at TTU is a university-designated research and support center that provides expert consulting and assistance on all manner of data collection, data management, and advanced statistical analyses.

Dr. Little is internationally recognized for his quantitative work on various aspects of indicator selection, parceling, modeling developmental processes, as well as his substantive developmental research in action-control processes and motivation, coping, and self-regulation.

Prior to joining TTU, Dr. Little has guided quantitative training and provided consultation to students, staff, and faculty at the Max Planck Institute for Human Development's Center for Lifespan Studies (1991–1998), Yale University's Department of Psychology (1998–2002), and researchers at University of Kansas (KU) (2002–2013, including as director of the RDA unit in the Lifespan Institute and as director of the Center for Research Methods and Data Analysis). In 2001, he was elected to membership in the Society for Multivariate Experimental Psychology, a restricted-membership society of



quantitative specialists in the behavioral and social sciences. In 2009, he was elected President of APA's Division 5 (Evaluation, Measurement, and Statistics). He founded, organizes, and teaches in the internationally renowned KU 'Stats Camps' each June and has given over 150 workshops and

talks on methodology topics around the world.

As an interdisciplinary-oriented collaborator, Dr. Little has published with over 280 persons from around the world in over 65 different peer-reviewed journals. He authored *Longitudinal Structural Equation Modeling* (2013) and has edited five books related to methodology, including the *Oxford Handbook of Quantitative Methods* and the *Guildford Handbook of Developmental Research Method*.

Dr. Little has served on numerous grant review panels for federal agencies such as NSF, NIH, and IES and private foundations such as the Jacobs foundation. He has been principal investigator or co-principal investigator on over 15 grants and contracts and he have served as a statistical consultant on over 60 grants and contracts. In the conduct of his collaborative research, he has participated in the development of over 12 different measurement tools, including the CAMI, Multi-CAM, BALES, BISC, I FEEL, and the form/function decomposition of aggression.

Presidential Award

Karrie A. Shogren, PhD

Karrie A. Shogren, PhD is an Associate Professor in the Department of Special Education, Associate Director of the Kansas University Center on Developmental Disabilities, and Associate Director of the Beach Center on Disability, all at the University of Kansas. Dr. Shogren's research focuses on self-determination and systems of support for adolescents and young adults with disabilities and she has a specific interest in the multiple, nested contextual factors that impact outcomes.

Dr. Shogren has published over 60 articles in peer-reviewed journals and is the author or co-author of five books, including the widely used textbook *Exceptional Lives: Special Education in Today's*



Schools. Dr. Shogren is also one of the co-authors of AAIDD's *Supports Intensity Scale—Children's Version and Adult Version* as well as a co-author of *Intellectual Disability: Definition, Classification, and Systems of Support*, the 11th Edition of the AAIDD's seminal definition of intellectual disability.

Dr. Shogren has received grant funding from several sources, including the Institute of Education Sciences (IES). Dr. Shogren is co-Editor of *Inclusion* an e-journal published by the AAIDD, and is an Associate Editor for *Intellectual and Developmental Disabilities* and *Remedial and Special Education*.



Dybwad Humanitarian Award Sheryl White-Scott, MD

Sheryl White-Scott, MD, has dedicated her entire professional life to the health and wellness of individuals with intellectual and developmental disabilities. Dr. White-Scott is the Associate Director of Community Health Services for the Medically Frail at AHRC/New York City. She is also a Medical Specialist for the Metro Developmental Disabilities Services Office in New York. These positions provide an opportunity to enhance the quality of life of individuals with intellectual and developmental disabilities and their families.

Dr. White-Scott received a bachelor's in Natural Sciences from Johns Hopkins University and a MD from SUNY Stony Brook School of Medicine. Her fellowship training in developmental disabilities was completed as part of the NYS Consortium of Medical Education in Developmental Disabilities program in affiliation with Montefiore Residency Program in Social Medicine, Children's Evaluation and Rehabilitation Center at Albert Einstein and Westchester Institute of Human Development at New York Medical College. She is board certified in internal medicine and is an Assistant Clinical Professor of Medicine in the Department of Internal Medicine at New York Medical College Valhalla, New York. This



educational path provided the basis for the ongoing professional commitment to service, training and research.

Dr. White-Scott is a member of the President's Committee for People with Intellectual Disabilities and a fellow in the American College of Physicians. She is also a member of the LEND

Advisory Board at Westchester Institute of Human Development and faculty for the Seminar on Family Centered Care and Developmental Disabilities at the Boggs Center on Developmental Disabilities at Rutgers Robert Wood Johnson Medical School. She is past president of the American Association of University Affiliated Programs (now Association of University Centers for Disabilities), past chair of the Health Promotion Committee and past chair of the Multicultural Special Interest Group of the AAIDD.

Dr. White-Scott has a special interest in health care delivery for women with developmental disabilities and individuals with developmental disabilities from minority populations. She has done numerous presentations on primary health care, prevention, aging, women's health and training medical professionals in the delivery of health services for individuals with developmental disabilities.

Early Career Award

Julie Lounds Taylor, PhD

Julie Lounds Taylor, PhD, is an assistant professor of Pediatrics and Special Education at Vanderbilt University. She is also an investigator at the Vanderbilt Kennedy Center, a Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Center. She received a bachelor's in psychology from Wheaton College, and a master's and doctorate in developmental psychology from the University of Notre Dame. She subsequently completed a post-doctoral fellowship in lifespan family research at the Waisman Center, University of Wisconsin-Madison, and was an assistant research scientist at the Waisman Center before joining the Vanderbilt University faculty in 2008.



Since arriving at Vanderbilt, Dr. Taylor's research has focused on the crucial transition to adulthood for youth with intellectual and developmental disabilities. She has co-authored 48 articles and book chapters on families, intellectual and developmental disabilities, autism, and the transition to adulthood. Her current work,

funded by Autism Speaks, is focused on investigating difficulties that youth with autism spectrum disorders face in employment, as well as employment's importance in future development. In another project funded by the National Institute of Mental Health, she is investigating how stress response, behavioral functioning, and environmental factors combine to place youth with autism at risk for a poor transition to adulthood. These research studies have confirmed the numerous difficulties faced by many youth with autism and their families during the transition years and beyond, and have produced some of the first data demonstrating the behavioral benefits of placing adults with ASD in the most independent vocational setting possible.

Dr. Taylor's interests in studying families of individuals with intellectual and developmental disabilities started during her undergraduate studies, while she was working with an organization providing recreational activities for individuals with disabilities. She observed that some families were thriving, whereas others had significant challenges. Through that experience, she became interested in how individual, family, and societal factors interact to promote healthy development. She pursued this interest in her graduate studies, examining how parenting relates to the emergence of mild intellectual disabilities in children born to adolescent mothers, and in her post-doctoral studies examining the impact of disability on parents and siblings.

Through all of this work, Dr. Taylor is quickly becoming an international expert in the transition to adulthood for youth with autism. Her research program holds great promise for improving transition services and policies, which in turn will improve quality of life of adults with intellectual and developmental disabilities and their families.

Education Award

Jan Rosemergy, PhD

Jan Rosemergy, PhD, is Deputy Director and Director of Communication and Dissemination at the Vanderbilt Kennedy Center for Research on Human Development at Vanderbilt University in Nashville, Tennessee. The Vanderbilt Kennedy Center is both a national Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Center and a University Center for Excellence in Developmental Disabilities. For the past 35 years at the Center, she has been dedicated to using communication and dissemination strategies to transfer knowledge generated by disability research into practice, where it can be used by families and professionals.

Dr. Rosemergy's academic degrees are in English. Like so many in the disability field, a personal encounter with disability led to a new career direction when close friends had a child with a developmental disability and she saw the difficulty that families had navigating complex service systems. As a nonscientist who values research, she communicates new knowledge in ways that are accessible for specific audiences, including families and citizens at large.

Dr. Rosemergy assists Vanderbilt Kennedy Center faculty and their

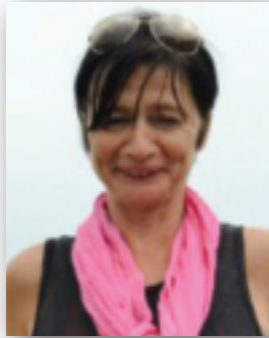


research teams with their dissemination needs. Over three decades, she has developed, wrote, and edited pieces for national dissemination, including the Center's newsletter, *Discovery*, and produces and disseminates accessible tip sheets, tool kits, and guides for families and professionals.

Dr. Rosemergy has forged partnerships with community and state disability organizations to promote evidence-based practices and principles of self-determination, strength-based and individualized services and supports, cultural competency, and community integration and inclusion. Realizing that photos are as important as words for communication, she was a lead organizer for *Kindred: Tennessee Portraits*, a photo exhibit and stories of rural and urban Tennesseans with disabilities. She was a lead creator of the *Tennessee Disability Pathfinder* information and referral service, its website and searchable database, used by self-advocates, family members, and professionals, and a model for other states. A recent collaborative project is *Tennessee Kindred Stories*, a searchable website where self-advocates and family members share their stories that inform public policy makers.

International Award Claudia Claes, PhD

Claudia Claes, PhD, is lecturer at the University College Ghent and a guest professor at Ghent University, Department of Special Education (Belgium). She worked for almost 25 years in the field of disabilities. In 2011, she received a doctorate in the pedagogical sciences at the university of Ghent, Faculty of Psychology and Pedagogical Sciences.



The title of her dissertation was *Inclusive Embedment of Person-Centred Supports*, a study of critical success factors. Among other things, she works and publishes with Drs. Schalock, Van Hove, and van Loon on supports and quality of life. In 2008 she developed, together with this group of colleagues, the *Personal Outcomes Scale (POS)*, an instrument that assess QOL-related outcomes and is translated in six languages, and, recently, this group developed and published the POS for children.

Dr. Claes was field editor for the *Encyclopedia for Quality of Life and Well-Being Research*. She is coordinator of E-QUAL, a center of Expertise on Quality of Life Studies. E-QUAL was founded in October 2011 by the Faculty of Education, Health and Social Work at the University College Ghent, and focuses on the acquisition of knowledge related to Quality of Life from a cross-disciplinary perspective. E-QUAL intends to systematically generate theoretical knowledge and

practical applications through applied scientific research, information dissemination, and education. E-QUAL primarily addresses professionals, facilities, policy bodies, interest groups and user groups who work with people in socially vulnerable situations.

E-QUAL enhances its profile by a strong cooperation between scientific research and the work in the field, which also includes important partners such as Ghent University, the Arduin Foundation in the Netherlands, and Openluchtopvoeding Brasschaat in Belgium. Dr. Claes works together with partners from different countries on community based rehabilitation programs and quality of life. She also works closely with parents advocating for inclusion. In India, she is starting to develop a cross-cultural research project on aging and quality of life.

Dr. Claes is author and co-author of numerous articles and book chapters. In addition to her academic work, she has served on numerous advisory committees regarding the implementation of the support paradigm in the field of disabilities. She is in great demand as a speaker at international conferences and trainings across Belgium and The Netherlands. She sits on the advisory board of the Flemish Foundation for people with disabilities in Belgium.

Media Award

Positive Exposure: The Spirit of Difference

Positive Exposure: The Spirit of Difference is photo and video presentation that explores the social and psychological experiences of people living with genetic, physical, cognitive, and behavioral conditions of all ages and ethno-cultural heritages. It premiered at the People's Genome Celebration at the



Smithsonian National Museum of Natural History in 2001 and has continued to exhibit in galleries, museums, and public arenas internationally.

Positive Exposure: The Spirit of Difference was created by award-winning fashion photographer Rick Guidotti following a chance encounter he had on a Manhattan street while on a break during a photo shoot. He saw a stunning girl at the bus stop: a girl with pale skin and white hair, a girl with albinism. Upon returning home he began a process of discovery—about albinism, people with genetic differences, and himself.

What started as a photographic project grew into an innovative non-profit arts organization that promotes human dignity for people with differ-

ences through creative arts productions. Today, the nonprofit organization Positive Exposure provides eye opening multi-media exhibitions that challenge stigmas and assumptions often associated with people with disabilities and offers educational and advocacy programs that reach around the globe, including

- photo shoots, interviews, and self-esteem workshops to empower people living with difference;
- lectures and workshops targeting medical schools, corporations, nursing and genetic counseling programs, universities, elementary and secondary schools;
- the Pearls Project, an interactive program for K–12 students, teachers, and healthcare providers; and an
- image database for print and media.

Positive Exposure: The Spirit of Difference reaches around the globe to promote a more inclusive, compassionate world where differences are celebrated.

View the photo gallery and learn more at the Positive Exposure website: positiveexposure.org.

Service Award

Elise McMillan, JD

Elise McMillan, JD has had an extraordinary influence on developing model evidence-based services for persons with intellectual and other developmental disabilities and their families on a community, state, and national level. Over almost 25 years, she has helped expand opportunities and improve systems, especially in transition, postsecondary education, and employment.



Ms. McMillan was a career journalist and attorney who rose to Managing Editor and then General Counsel of the *Nashville Banner*. Since the birth of her middle child, Will, who has Down syndrome, she and her entire family, including husband Tom, son Jim, and daughter Cate, have all become involved in supporting people with disabilities to be part of the community.

In 1995, Ms. McMillan joined the Vanderbilt Kennedy Center. She has dramatically strengthened the connections among Center researchers, staff, and families; and has promoted the integration of research and training into services. Her contributions were crucial in our becoming a University Center for Excellence in Developmental Disabilities (UCEDD) in 2005. As UCEDD Co-Director, she oversees more than 40 programs, including Tennessee Disability Pathfinder, Multicultural Outreach, Sibling Programs, summer camps, Arts and Disabilities, Henderson Training Series

for Educators, and Next Steps at Vanderbilt. She holds an appointment as Senior Associate in the VUMC Department of Psychiatry.

Ms. McMillan is a leader, serving as a board member and officer of many local, state, and national disability organizations. Since 2008, she has

co-chaired the Nashville Mayor's Advisory Committee on Special Education, co-authoring three reports, the most recent focused on improving transition from secondary education. She was a founding member and continues as a leader of the Tennessee Alliance on Postsecondary Education for Students with Intellectual and Developmental Disabilities. She led development of Next Steps at Vanderbilt, Tennessee's first postsecondary education program for people with intellectual disability, and is its faculty director. She serves on the boards of The Arc US and The Arc Tennessee Boards and chairs The Arc US Policy and Position Statements Committee. She is a member of the Tennessee Council on Developmental Disabilities and the board of the Disability Law and Advocacy Center of Tennessee. She was appointed by the Governor to the Tennessee Employment First Task Force and is co-PI on an Administration on Intellectual and Developmental Disabilities' five-year systems change grant with multiple state partners to improve employment of Tennesseans with disabilities.

Student Award

Dora Raymaker, MS

Dora Raymaker, MS, is a doctoral candidate in the Systems Science Department at Portland State University (PSU) and the Co-Director of the Academic Autistic Spectrum Partnership in Research and Education (AASPIRE). Ms. Raymaker's research interests lie at the dynamic crossroads of science, technology, policy, and human emancipation, with a focus on participatory action research to improve the lives of individuals with developmental disabilities. She brings multiple perspectives to her work, including her experiences as a person with autism.

After a ten-year career in technology, Ms. Raymaker entered the Systems Science Master's program at PSU to pursue her life-long interest in complex systems. During that time she became involved, via her advocacy work, in community based participatory research. Together with her academic partner, she founded AASPIRE to conduct research in partnership with the autism community.



Over time, Ms. Raymaker's scientific interests shifted from the harder technology-based domains to advocacy interests, including research ethics, intervention for community-identified issues, and the complex dynamics of community-engaged research as a potential vehicle for systems change. With the

support, mentorship, and experiences she gained as a community partner, Ms. Raymaker was able to return to PSU to pursue a doctorate. Her doctoral work focuses on the use of systems thinking and community based participatory research to develop an accessible web site about healthcare for individuals on the autism spectrum.

Ms. Raymaker plans to continue to conduct community-engaged research and encourage the inclusion of people with developmental disabilities in research as an academic investigator. She hopes that her work may ultimately nudge science, policy, and society one step closer to systems change that people with developmental disabilities want to see.

Past Presidents

The history of the AAIDD is long and distinguished. Our tradition, professional standing, and leadership in the area of intellectual and Developmental disabilities are exemplified in the persons of our Presidents. Our former Presidents are:

1876-1877	Edouard Sequin, MD	1910-1911	Arthur R.T. Wylie, MD
1877-1878	Hervey B. Wilbur, MD	1911-1912	H. G. Hardt, MD
1878-1879	G. A. Doren, MD	1912-1913	Allan E. Carrol, MD
1879-1880	H. M. Knight, MD	1913-1914	J. K. Kutnewsky, MD
1880-1881	Charles T. Wilbur, MD	1914-1915	H. H. Goddard, PhD
1881-1882	George W. Brown, MD	1915-1916	Charles Bernstein, MD
1882-1884	J. Q. A. Stewart, MD	1916-1917	E. J. Emerick, MD
1884-1885	A. H. Beaton, MD	1917-1918	George L. Wallace, MD
1885-1886	F. M. Powell, MD	1918-1919	Charles S. Little, MD
1886-1887	William B. Fish, MD	1919-1920	George S. Bliss, MD
1887-1888	George H. Knight, MD	1920-1921	H. A. Haynes, MD
1888-1889	J. C. Carson, MD	1921-1922	Joseph H. Ladd, MD
1889-1890	A. C. Rogers, MD	1922-1923	C. Banks McNairy, MD
1890-1891	J. T. Armstrong, MD	1923-1924	Walter E. Fernald, MD
1891-1892	Isaac N. Kerlin, MD	1924-1925	Groves B. Smith, MD
1892-1893	Walter E. Fernald, MD	1925-1926	Arthur R. T. Wylie, MD
1893-1894	A. E. Osborne, MD	1926-1927	Benjamin W. Baker, MD
1894-1895	A. W. Wilmarth, MD	1927-1928	Edward R. Johnstone
1895-1896	Samuel J. Fort, MD	1928-1929	George E. McPherson, MD
1896-1897	Martin W. Barr, MD	1929-1930	George L. Wallace, MD
1897-1898	George A. Brown, MD	1930-1931	H. H. Ramsey, MD
1898-1899	Mary J. Dunlap, MD	1931-1932	Harvey M. Watkins, MD
1899-1900	Alexander Johnson	1932-1933	Howard W. Potter, MD
1900-1901	W. A. Polglase, MD	1933-1934	Ransom A. Greene, MD
1901-1902	F. W. Keating, MD	1934-1935	Mary M. Wolfe, MD
1902-1903	J. M. Murdoch, MD	1935-1936	Edgar A. Doll, PhD
1903-1904	Edward R. Johnstone	1936-1937	Benjamin O. Whitten, MD
1904-1905	A. H. Beaton, MD	1937-1938	Harry C. Storrs, MD
1905-1906	George Mogridge, MD	1938-1939	Neil A. Dayton, MD
1906-1907	W. H. C. Smith, MD	1939-1940	Frederick Kuhlmann, PhD
1907-1908	Charles Bernstein, MD	1940-1941	Meta L. Anderson, PhD
1908-1909	W. N. Bullard, MD	1941-1942	Fred O. Butler, MD
1909-1910	Miss Mattie Gundry	1942-1943	Horatio M. Pollock, PhD

Past Presidents (con't.)

1943-1944	C. Stanley Raymond, MD	1978-1979	Richard C. Scheerenberger, PhD
1944-1945	E. Arthur Whitney, MD	1979-1980	Marjorie H. Kirkland, MSSW
1945-1946	Mabel A. Matthews	1980-1981	H. Carl Haywood, PhD
1946-1947	Warren G. Murray, MD	1981-1982	Frank A. Borreca, EdD
1947-1948	Lloyd N. Yepsen, PhD	1982-1983	A. Gail O'Connor, PhD
1948-1949	Edward J. Humphreys, MD	1983-1984	Herbert J. Grossman, MD
1949-1950	Mildred Thomson	1984-1985	B. R. (Bill) Walker, PhD
1950-1951	Richard H. Hungerford	1985-1986	H. Rutherford Turnbull III, LLB, LLM
1951-1952	Edward J. Engberg, MD	1986-1987	Harold Michal-Smith, PhD
1952-1953	Bertha M. Luckey, PhD	1987-1988	Valaida S. Walker, EdD
1953-1954	Arthur T. Hopwood, MD	1988-1989	Robert G. Griffith, EdD
1954-1955	Gale H. Walker, MD	1989-1990	James W. Ellis, JD
1955-1956	Arthur E. Westwell, DMD	1990-1991	Robert R. Bruininks, PhD
1956-1957	Thomas L. McCulloch, PhD	1991-1992	Jack A. Stark, PhD
1957-1958	Chris J. DeProspro, EdD	1992-1993	Michael R. Dillon, EdD
1958-1959	George Tarjan, MD	1993-1994	David L. Braddock, PhD
1959-1960	Frances M. Coakley	1994-1995	Karen L. Middendorf
1960-1961	Edward L. Johnstone	1995-1996	William E. Kiernan, PhD
1961-1962	Herschel W. Nisonger	1996-1997	Pamela C. Baker, PhD
1962-1963	William Sloan, PhD	1997-1998	Robert L. Schalock, PhD
1963-1964	George L. Wadsworth, MD	1998-1999	Stanley S. Herr, JD, DPhil
1964-1965	Harvey A. Stevens	1999-2000	Bernard R. Wagner, PhD
1965-1966	I. Ignacy Goldberg, EdD	2000-2001	Cathy Ficker Terrill, MS
1966-1967	Marguerite J. Hastings	2001-2002	Steven F. Warren, PhD
1967-1968	Harvey F. Dingman, PhD	2002-2003	Ruth A. Luckasson, JD
1968-1969	Richard Koch, MD	2003-2004	Ann P. Turnbull, EdD
1969-1970	Wesley D. White, EdD	2004-2005	David L. Coulter, MD
1970-1971	Horace Mann, PhD	2005-2006	Valerie J. Bradley, MA
1971-1972	Robert L. Erdman, EdD	2006-2007	Henry "Hank" A. Bersani, PhD
1972-1973	Michael J. Begab, PhD	2007-2008	David A. Rotholz, PhD
1973-1974	David Rosen, MS	2008-2009	Steven M. Eidelman, MSW
1974-1975	James D. Clements, MD	2009-2010	Joanna L. Pierson, PhD
1975-1976	Sue Allen Warren, PhD	2010-2011	Michael L. Wehmeyer, PhD
1976-1977	Burton Blatt, EdD	2011-2012	Sharon C. Gomez
1977-1978	Margaret J. Giannini, MD	2012-2013	Marc J. Tassé, PhD

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June 1–4, 2015

