Beth Marks, PhD, RN, FAAN Curriculum Vitae

GENERAL INFORMATION

Contact:Rehabilitation Research and Training Center on Developmental Disabilities and
Health (RRTCDD)
Department of Disability and Human Development (DHD), M/C 626
College of Applied Health Sciences (CAHS), University of Illinois at Chicago
1640 West Roosevelt Road, Room 736
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EDUCATION

University of Illinois at Chicago (UIC), College of Nursing (CON)

Postdoctoral Trainee, June, 1997 to June, 2000

NIH funded research training program in primary health care research, participatory health promotion research for people with disabilities using a social model.

Doctor of Philosophy, 1996

- Public Health Nursing and Developmental Disabilities
- University of Cincinnati College of Nursing (CON)

Master of Science in Nursing, 1991

Occupational Health/Community Health Nursing and Developmental Disabilities **Bachelor of Science in Nursing**, Cum Laude, 1985

PROFESSIONAL EXPERIENCE

Associate Director for Research. Rehabilitation Research and Training Center on Aging with Developmental Disabilities (RRTCADD), Department for Disability and Human Development (DHD). UIC, Chicago, IL, (2002 –); Assistant Director (2001-2002).
Research Associate Professor. UIC, CAHS, DHD, Chicago, IL (2011 –).
Research Assistant Professor. UIC, CAHS, DHD, Chicago, IL 2002 - 2011.
Adjunct Faculty. College of Nursing at UIC (2004 –) & Rush University (2004 –).
Assistant Professor. Northern Illinois University, DeKalb, IL. (2000, 2005, 2010).
Senior Research Associate. College of Nursing, Primary Health Care Center and CAHS, RRTCADD, DHD, UIC Chicago, IL (2000 - 2001).
Postdoctoral Fellow. UIC, College of Nursing (CON), Primary Health Care and CAHS, RRTCDD, DHD, Chicago, IL (1997 – 2000).
Senior Research Specialist in Health Sciences. UIC, CON (1996 – 1997) and CAHS, DHD, Center for Emergent Disability, DHD, Chicago, IL (1996).
Research Assistant. UIC, CON and CAHS, Chicago, IL (1992 to 1996).

Nursing career in Cincinnati, Ohio from 1985 to 1992 consisted of employment as a staff/charge nurse on a medical unit, which expanded onto geriatric and general psychiatric units, adolescent chemical dependency unit, home care, medical/case management; and, as a NIOSH and Trainee in developmental disabilities, gained experience in occupational health nursing, inclusive of people with disabilities.

INTERNATIONAL, NATIONAL, AND LOCAL FIELD WORK

- 2015 Directed the *Promoting Health & Safety for Workers with Disabilities: Realizing the Promise of the ADA* in Chicago, IL. Conference brought together disparate professionals and advocates to discuss legislative changes to recruit, hire, promote, and retain employees with disabilities, workers with chronic conditions, workers with work-related injuries, and workers experiencing age-related changes: <u>http://rrtcadd.org/worker-health/</u>.
- 2009-2010 Capacity building among health professionals in Ecuador to promote health among persons with IDD through the Global Health Leadership Office (GHLO)/WHO Collaborating Center and the DHD, and Causes for Change International - Ecuador.
- 2007-2008 Feasibility Study to advance nursing education at Bel-Air Sanatorium and Hospital in Panchgani, Maharashtra, India through the GHLO/WHO Collaborating Center, DHD, UIC, and Bel-Air Sanatorium and Hospital.
- 2000 Nursing and midwifery research agenda with Naemma Al-Gasseer, Chief Nurse Scientist for Nursing and Midwifery at the World Health Organization.
- 1999 Collaboration between University of Illinois at Chicago, College of Nursing and Moise Nepan of Credo in Burkina Faso for HIV/AIDS prevention and education.
- 1997 to 1999 Needs assessment with the Evanston Health and Human Services to identify experiences of people with disabilities in Evanston, Ill.
- 1997 Collaboration between UIC, CON and *Lithuanian Mercy Lift* for a country-wide HIV/AIDS prevention and education.
- 1990 to 1991 –Collaboration with University of Cincinnati, CON and the Ohio Department of Developmental Disabilities for *Statewide Occupational Health Needs Assessment*.

HONORS/AWARDS

2015	Recipient of a University of Cincinnati College of Nursing 125th Anniversary
	Alumni Legacy Award
2010	Open the Door, Get 'Em a Locker: Educating Nursing Students with Disabilities
	selected for the Southwest Conference on Disability Film Festival
2009	Recipient of the 2009 University of Cincinnati College of Nursing Alumni
	Association Distinguished Alumni Award
2009	Institute of Medicine of Chicago Fellow
1995-	Honor Society of Nursing, Sigma Theta Tau International, Alpha Lambda Chapter
1992-1994	Institute for Disability and Human Development Graduate Fellowship, UIC.
1992	Represented the University of Cincinnati College of Nursing and Health at the
	16th Annual Midwest Nursing Research Society Conference
1990-1991	Maternal Child Health (MCH) Long-term Traineeship in an Interdisciplinary
	Training Program for Developmental Disorders, University Affiliated Cincinnati
	Center for Developmental Disorders (UACCDD)
1989-1990	Public Health Service National Institute for Occupational Safety and Health
	(NIOSH) Educational Resource Center Traineeship in Occupational Health
	Nursing. Assessed occupational health issues for adults with IDD

THESIS/DISSERTATION

Marks, B.A. (1996). Conceptualizations of Health among Adults with Intellectual Impairments, Unpublished Doctoral Dissertation, University of Illinois at Chicago. Dissertation Abstracts International. Volume: 57-11, Section: B, page: 6877. Marks, B.A. (1991). Revision and Pilot Testing of a Decision-Making Questionnaire for Adults with Mental Retardation, Unpublished Masters Thesis, University of Cincinnati. **CURRENT RESEARCH SUPPORT** Total current ((6,966,941)) and completed projects ((8,032,035) = (14,998,976)HDI 2019 Sheppard-Jones (PI) 2-1-19 to 7-31-20 \$260,580 Kentucky Department of Workforce Investment/ (\$2,500,000). PI of Subcontract with University of Kentucky, HDI. RETAINing Kentucky's Workforce through Universal Design (Role: Implementation) **Donohue-Chase (PI)** 1-1-19 to 12-31-19 NR 2019 \$19,000 Healthcare Foundation of Northern Lake County (\$70,000). PI of Subcontract with NorthPointe Resources. OptimalRx: When Less is More (Role: Implementation and Evaluation) 2017- AG022849-11 Marks (PI) 06/01/2017-05/31/2019 \$40.000 Midwest Roybal Center for Health Promotion and Translation, NIH National Institute on Aging HealthMatters@24/7 **PS 2017** 01/01/2017-12/31/2019 Reile (PI) \$40,000 Ohio Developmental Disabilities Council. PI of subcontract \$13,000 through Project SEARCH *Healthy Lifestyles for People with Disabilities: Project SEARCH and HealthMatters*TM *Program* 2014-03878 Hughes (PI)/Marks (Co-I) 09/30/2003-05/31/2019 \$1.620.595 NIH National Institute on Aging Roybal Center for Health Promotion and Translation 90RT5020-01-00 Marks (PI) 10-1-13 to 09-30-19 \$601,766 National Institute on Disability and Rehabilitation Research (NIDRR), RRTCDD HealthMatters Program Impact Study: Multi-State Systematic Approach Heller (PI)/Marks (Co-I) 90RT5020-01-00 10-1-13 to 9-30-19 \$4,375,000 National Institute on Disability and Rehabilitation Research (NIDRR) Rehabilitation Research and Training Center on Developmental Disabilities and Health **COMPLETED RESEARCH SUPPORT 2007-2012** (\$8,032,035) 2016-00301492 Sisirak (PI)/Marks (Co-I) 05/01/2016-05/31/2018 \$28,833 Walmart Foundation. Subcontract through Association of University Centers on Disabilities Nutrition is for Everyone **The ARC 2017** Marks (PI) 01/01/2017-12/31/2018 \$15,000 *The Arc HealthMeets Collaborative* **IDPH Grant** Marks (PI) 8-1-13 to 12-31-15 \$24,467 Illinois Department of Public Health HealthMatters Program IL Scale Up Arc Grant 2014 Marks (PI) 8-1-13 to 12-31-15 \$6.000

HealthMatters Program Scale Up in the Arc

COMPLETED RESEARCH SUPPORT, cont.

CIF 2012	Sisirak (PI)/Marks (Co-I)	1-1-12 to 10-1-13	\$20,000	
Center for Independent Futures. Subcontract through The Chicago Community Trust				
Evaluation of the Fu	ll Life Futures Program in Chi	icago Public Schools Pilot		
NRI 2011	Donohue-Chase (PI)	5-1-11 to 10-30-13	\$750,000	
IL Department of Pu	blic Health. PI of Subcontract	(\$90,000) through NorthPointe R	esources	
Health Matters Diabetes Education Awareness and Prevention for People with IDD				
1RC4HD066915-01	Marks (PI)	9-1-10 to 8-31-13	\$1,000,000	
Eunice Kennedy Shriver National Institute of Child Health & Human Development				
Community-Academ	ic Partnership: Infrastructure	to Improve Health for People with	h DD	
SOI2010	Marks (PI)	7-1-10 to 6-30-12	\$100,000	
Special Olympics Int	ternational			
Peer-to- Peer: Athlete Health Coaches Pilot Intervention				
H133B080009	Heller (PI)/Marks (Co-I)	10-1-08 to 9-30-13	\$4,375,000	
National Institute on	Disability and Rehabilitation I	Research (NIDRR)		
Rehabilitation Resea	rch and Training Center on Ag	ging with Developmental Disabili	ties	
H133B080009	Marks (PI)	10-1-08 to 9-30-13	\$882,135	
NIDRR, Rehabilitati	on Research and Training Cen	ter on Aging with Developmental	Disabilities	
Sustainable Health I	nitiative Programs: Translatin	g Knowledge through Distance L	earning	
HRSA-08-148	Cutler (PI)/Marks (Co-I)	9-1-08 to 8-31-11	\$550,000	
Illinois Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND):				
Community Consortium (ILCC). Discipline Coordinator for Nursing.				
E7651	Marks (PI)	8-1-07 to 9-30-08	\$48,500	
Midwest Roybal Center for Health Promotion and Behavior Change: Pilot Competition, National				
Institute on Aging				
Continuity of Care for	or People Aging with I/DD: A	Pilot Training Program		
G6844	Marks (PI)	4-1-07 to 3-31-10	\$37,100	
Partnership with Nor	thPointe Resources Inc. (Baxte	er Foundation)		
Health and Wellness	Capacity Building Project: "C	Getting the Memo"		
H133B031134	Marks (PI)	10-1-03 to 9-30-08	\$150,000	
National Institute on	Disability and Rehabilitation I	Research		
Healthy Communities for Adults with Intellectual and Developmental Disabilities: Evaluating the				
Efficacy of Two Trai	n-the-Trainer Approaches (Pa	per-Based and Web-Based)		
2005-2270	Heller (PI)/Marks (Co-I)	9-1-06 to 12-31-07	\$5,000	
Easter Seals				
Health Promotion for Adults with Intellectual and Developmental Disabilities (I/DD)				
H8721	Marks (PI)	6-1-07 to 7-31-08	\$40,000	
Illinois Council on Developmental Disabilities				
Building Capacity with Pediatric Residents to Promote Health Advocacy among People with DD				
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RESEARCH FROM 1994-2006 (\$521,252.00) (funding included to demonstrate pattern of the history of development and the length of time required to move research into systems change, capacity building for sustainable practice and policy supporting health promotion for people with IDD).

Foundations and Non-Profits: Easter Seals; The Chicago Community Trust; Special Olympics International; Retirement Research Foundation

Government: Department of Labor

Training Grants: National Institute of Nursing Research (NINR), National Research Service Award (NRSA) Institutional Postdoctoral Research Training in Primary Health Care; NINR, NRSA Pre-doctoral Research Training Grant.

EVIDENCE-BASED CURRICULUM/PROGRAM DEVELOPMENT

- Health Matters 12-Week Program: Exercise and Nutrition Health Education Curriculum for Adults with Developmental Disabilities (Marks, Sisirak, & Heller, 2010, 2006, 2004, 2001), Brookes Publishing: Philadelphia. <u>Evidence-based curriculum</u> empowering people with IDD to achieve health goals through an instructor-led health promotion program. Funded by National Institute on Disability and Rehabilitation Research (NIDRR), Center for Disease Control and Prevention, and National Institute on Aging (https://tinyurl.com/hjnahdk).
- HealthMatters Program: Train-the-Trainer Certified Instructor Workshop (Marks & Sisirak, 2005). Evidence-based program transforming systems for health and wellness where people with DD live, work, and recreate. Funded by National Institute on Disability and Rehabilitation Research and Retirement Research Foundation (https://tinyurl.com/jb44bkz).
- 3. HealthMessages Program: Peer-to-Peer (Marks, Sisirak, Medlen, & Magallanes, 2012). <u>Evidence-based program</u> teaching people with IDD to become a Peer Health Coaches (PHCs) to encourage peers to change health behaviors. Funded by Special Olympics International (Centers for Disease Control and Prevention's Disability and Health Branch), the RRTCADD (National Institute on Disability and Rehabilitation Research), and HealthMatters Community Academic Partnership (Eunice Kennedy Shriver National Institute of Child Health & Human Development) (<u>https://tinyurl.com/hj4hg77</u>).
- HealthMatters 4Kids: Today Counts for Preventing Diabetes and Other Chronic Conditions: Instructor's Train the Trainer Program (Marks, B., Donohue-Chase, D., Arora, P. & Pierce, J. 2013). Evidence-informed program preventing diabetes and other chronic conditions in children with IDD by raising awareness among parents, teachers, and health care professionals. Funded by Illinois Department of Public Health, subcontract through NorthPointe Resources (NR) (https://tinyurl.com/heb8joq).
- HealthAdvocacy Program: Promoting Health for People with Disabilities (Marks, Sisirak, & Cutler, 2008). Evidence-informed program promoting health for people with disabilities. Funded by Illinois Council on Developmental Disabilities (https://tinyurl.com/gnxsddq).
- HealthAlert: Observe (and Report) Early Signs and Symptoms of Changes in Health (Marks & Sisirak, 2008). Evidence-informed program observing (and reporting) signs of health changes among people with IDD. Funded by the Midwest Roybal Center for Health Promotion and Behavior Change, National Institute on Aging (https://tinyurl.com/jed7cmx).

PUBLICATIONS

Refereed Publications

- Marks, B., Sisirak, J., Magallanes, R.E., Krok, K., & Donohue-Chase, D. (**in press**) Efficacy of a Health Messages Peer-to-Peer Program for People with Intellectual Disabilities, *Health Education Research*.
- Marks, B. & Sisirak, J. (**in press**) Impact of the HealthMatters Train-the-Trainer Program on the Health and Health Behaviors of Staff Supporting Adults with Intellectual and Developmental Disabilities, *Workplace Health & Safety*.
- Chen, M.-D., Chang, J.-J., Kuo, C. -C., Yu, J. -W., Huang, M. -F., Marks, B., Chang, Y. -C. (2017). A pilot comparative study of one-way versus two-way text message program to promote physical activity among people with severe mental illness, Mental Health and Physical Activity (2017), https://doi.org/10.1016/j.mhpa.2017.09.010
- Marks, B. & Sisirak, J. (2017). NPs Promoting Physical Activity: People with Intellectual and Developmental Disabilities. *The Journal for Nurse Practitioners*, *13(1)*, e1–e5. DOI: 10.1016/j.nurpra.2016.10.023
- Ailey, S. H. & Marks, B. (2016). Technical Standards for Nursing Education Programs in the 21st Century. *Rehabilitation Nursing*. doi: 10.1002/rnj.278
- Marks, B. & McCulloh, K. (2016). Success for Students and Nurses with Disabilities: A Call to Action for Nurse Educators, *Nurse Educator*, 41(1), 9-12. doi: 10.1097/NNE.0000000000212.
- Neal-Boylan, L., Marks, B., McCulloh, K.J. (2015). Supporting Nurses and Nursing Students with Disabilities, *American Journal of Nursing*, 115(10), 11. doi: 10.1097/01.NAJ.0000471915.49472.ab.
- Ronneberg, C., Peters-Beumer, L., Marks, B., & Factor, A. (2015). Promoting Collaboration between Hospice and Palliative Care Providers and Adult Day Services for Individuals with Intellectual and Developmental Disabilities: Findings from a Training Intervention. *OMEGA Journal of Death and Dying*, 70(4), 380–403.
- Heller, T., Fisher, D., Marks, B., & Hsieh, K. (2014) Interventions to promote health: crossing networks of intellectual and developmental disabilities and aging. *Disability and Health Journal*, *7, S24-S32*.
- Anderson, L.L., Humphries, K., McDermott, S., Marks, B., Sisirak, J., & Larson, S. (2013). The State of the Science of Health and Wellness for Adults With Intellectual and Developmental Disabilities. *Intellectual and Developmental Disabilities*, 51(5), 385-398.
- Marks, B., Sisirak, J., & Chang, Y.C. (2013). Efficacy of the *HealthMatters Program* Train- the-Trainer Model, *Journal of Applied Research in Intellectual Disabilities*, 26(4), 319-334.
- Marks, B. & Sisirak, J. (2011). Interpreting Conceptualizations of Health Among Persons with Disabilities Through Critical Social Theory. *Journal for the Anthropological Study of Human Movement*, 16(1 & 2).
- Marks, B., Sisirak, J., Heller, T., Wagner, M. (2010). Evaluation of Community-Based Health Promotion Programs for Special Olympics Athletes. *Journal of Policy and Practice in Intellectual Disabilities*, 7(2), 119–129.

Refereed Publications, cont.

- Marks, B., Sisirak, J., Hsieh, K. (2008). Health services, health promotion, and health literacy: Report from the State of the Science in Aging with Developmental Disabilities Conference. *Disability and Health Journal*, 1(3), pp. 136-142.
- Marks, B. (2007). Cultural Competence Revisited: Nursing Students with Disabilities. *Journal of Nursing Education*, 46(2), 70-74.
- Heller, T., Hsieh, K., Marks, B., & Sisirak, J. (2005). 1st IASSIDD Asian-Pacific Conference Taipei, Taiwan June 12-15, 2005 Abstracts. *Journal of Policy and Practice in Intellectual Disabilities* 2 (3-4), 176–220.
- Marks, B.A. & Heller, T. (2003). Bridging the equity gap: Health promotion for adults with developmental disabilities. *Nursing Clinics of North America*, *38(2)*, 205-228.
- Marks, B.A., Brown, A., Hahn, J.E. & Heller, T. (2003). Nursing Care Resources for Individuals with Intellectual and Developmental Disabilities across the Lifespan. *Nursing Clinics of North America*, 38(2), 373-393.
- Ailey, S. Marks, B.A., & Hahn, J.E. (2003). Promoting Sexuality Across the Lifespan for Individuals with Intellectual and Developmental Disabilities. *Nursing Clinics of North America*, 38(2), 229-252.
- Heller, T., Ying, G., Rimmer, J.H., & Marks, B.A. (2002). Determinants of exercise in adults with cerebral palsy. *Public Health Nursing 2002; 19(3):*223-31.
- Norr, K.F., McElmurry, B.J., Slutas, F.M., Christiansen, C.D., Marks, B.A., & Misner, S.J. (2001) Mobilizing Lithuanian health professionals as community peer leaders for AIDS prevention: An international primary health care collaboration. *Nursing and Health Care Perspectives*, 22(3), 140-145.
- Marks, B.A. (2000). Jumping Through Hoops and Walking on Egg Shells or Discrimination, Hazing, and Abuse of Students with Disabilities? *Journal of Nursing Education*, *39(5)*, 205-210.
- Fujiura, G.T., Fitzsimons, N., Marks, B.A., & Chicoine, B. (1997). Predictors of BMI among adults with Down Syndrome: The social context of health promotion. *Research in Developmental Disabilities*, 18(4), 261-274.
- Rimmer, J.H., Braddock, D., & Marks, B.A. (1995). Health characteristics and behaviors of adults with *mental retardation residing in three living arrangements*. *Research in Developmental Disabilities*, *16*, *489*-499.

Non-Refereed Publications

- McCulloh, K. & Marks, B. (2016). FAQ's: Challenges and Strategies for Nursing Students and Nurses with Disabilities. *New Hampshire Nursing News* (https://www.nh.gov/nursing/index.htm), 40(1), 6-7.
- Sisirak, J. & Marks, B. (2015). Health and Wellness Strand: Recommendations From National Goals Conference 2015. *Inclusion, 3(4),* 242-249, http://aaiddiournals.org/doi/abs/10.1352/2326.6988.3.4.242
- http://aaiddjournals.org/doi/abs/10.1352/2326-6988-3.4.242.
- Sisirak, J. & Marks, B. (2015). AAIDD Research Brief: Health and Wellness for People with IDD. https://aaidd.org/docs/default-source/National-Goals/health-and-wellness-for-people-with-idd-2.pdf?sfvrsn=0.

Non-Refereed Publications, cont.

- McCulloh, K. & Marks, B. (*Jan/Feb*, 2015). National Organization of Nurses with Disabilities asks: What would you do? *The American Nurse Today a Publication of the American Nurses Association http://www.theamericannurse.org/2015/03/01/national-organization-of-nurses-with-disabilities-asks-what-would-you-do/, 11.*
- McCulloh, K. & Marks, B. (2015). FAQ's: RNs Who Become Disabled After Receiving Their License. *New Hampshire Nursing News (https://www.nh.gov/nursing/index.htm)*, 39(4), 9.
- McCulloh, K. & Marks, B. (2015). The Voice of Disability in Nursing. *New Hampshire Nursing News (www.nh.gov/nursing/index.htm)*, 39(1), 4.
- Marks, B. & Sisirak, J. (2012). *HealthMatters* for People with Developmental Disabilities: Take Charge! *National Gateway to Self-Determination*.
- Marks, B. & Sisirak, J. (2012). Preventing Health Problems among People with Intellectual and Developmental Disabilities: DSPs' Role in Observing and Reporting Early Signs and Symptoms. *Frontline Initiative*, 10(2).
- Marks, B. & Sisirak, J. (2010). Age-Related Changes for Adults with Developmental Disabilities. *Impact Newsletter*, 23(1), 24-25, 34.
- Marks, B. & Sisirak, J. Promoting Wellness for People Aging With Disabilities: The Challenges for Providers. (February 2008) *Maximizing Human Potential*. American Society on Aging.

Published Abstracts

- Sisirak, J. & Marks, B. (2010). Lessons Learned: Community Based Train the Trainer Health Promotion Programming for People with ID. Abstracts of the Third International Conference of IASSIDD Europe, 20-22 October, 2010, Rome. *Journal of Applied Research in Intellectual Disabilities*, 23(5), 467.
- Carroll, S.M., Evans, B., McCulloh, K., Marks, B., & Smith, M. (2005). *Book Review: Nursing Students with Disabilities: Change the Course, by Donna Maheady,* AHEAD (Association on Higher Education and Disability) Alert Newsletter, *November*.

Videotape Productions

HealthMatters Program YouTube Channel https://tinyurl.com/yapasq4q.

- Marks, B. & Sisirak, J. (2012). HealthMatters: Exercise, Nutrition, and Health Education Program. This DVD corresponds with the evidence-based training entitled HealthMatters Train-the-Trainer: Certified Instructor Workshop as a visual representation of instructional methods for direct support professionals.
- Evans, B.C. & Marks, B. (2009). *Open the Door, Get 'Em a Locker: Educating Nursing Students with Disabilities* <u>https://tinyurl.com/ycv6xq8g</u>. Documentary film chronicles the experience of a nursing student who entered a baccalaureate program using a wheelchair. The 23-minute film provides a forum for the voices of nursing students, faculty, administrators, and agency nursing staff to discuss trials and triumphs encountered during this experience. Real life example exploring roles and responsibilities in nursing education, experiential learning, shifting perspectives, and being a part of old ways turning into new ways in the world of nursing. Evans & Marks, Chicago, IL.

Assessment Tools

- Sisirak, J. & Marks, B. (2008). *HealthMatters Assessment of Organizational Need and Capacity*. Evaluates organizational need and capacity for health promotion among community organizations in relation to organizational culture, internal and external resources, employee knowledge, and employee self-confidence. HealthMattersTM 2012, Chicago, IL.
- Marks, B., Sisirak, J., & Plachy, T. (2007). *Head-to-Toe Signs and Symptoms Checklist*. This checklist was adapted from Lewis, Lewis, Leake, King, & Lindemann (2001) and is for direct support staff and healthcare providers (HCPs) to communicate emerging signs and symptoms of health changes and action plans among people receiving supports. HealthMattersTM 2010, Chicago, IL.
- Marks, B. (1998). *Community Assessment Profile*. Survey profiles the lives of people with disabilities living in the community and prioritize their issues and concerns within community domains, such as, housing, education, employment, health care/social services, transportation, shopping, religion/spirituality, media, culture/arts/recreation, and safety/public services using a social model perspective. HealthMattersTM 2010, Chicago, IL.
- Marks, B. (1996). *Definitions of Health Scale*. People with IDD report their "definitions of health." HealthMattersTM 2010, Chicago, IL.

Newsletters/Periodical Interviews/Social Media

- HealthMatters Alerts (Created 3-1-12). Listserv for the HealthMatters Program (1056 Subscribers).
- HealthMatters Program. (January/February 2017). Project SEARCH at Cincinnati Children's Awarded Grant from Ohio DD Council to Incorporate Health Matters Curriculum. *HealthMatters Program Online Newsletter*, 2(1) (https://tinyurl.com/hkfczy4).
- HealthMatters Program. (November/December 2016). HealthMatters Program North Carolina and HealthMatters Program Maryland. *HealthMatters Program Online Newsletter*, 1(7) (https://tinyurl.com/jyfxpah).
- The Arc. (October 2016). Celebrating Healthier Lives. The Arc eNews (https://tinyurl.com/z42emha).
- HealthMatters Program. (September/October 2016). The Power of Wellness Committee Setting Up Your Organization for Success. *HealthMatters Program Online Newsletter*, 1(6) (https://tinyurl.com/jrbjfza).
- HealthMatters Program. (July/August 2016). Introducing HealthMatters, Maryland! Initiative. *HealthMatters Program Online Newsletter*, 1(5) (https://tinyurl.com/h2ej9rv).
- HealthMatters Program. (June 2016). HealthMatters, Kentucky! Still Going Strong. *HealthMatters Program Online Newsletter*, 1(4) (<u>https://tinyurl.com/jbdwdn8</u>).
- HealthMatters Program. (April/May 2016). North to Alaska: HealthMatters Program Delights Eagle Crest Clients and Employees, *HealthMatters Program Online Newsletter*, 1(3) (<u>https://tinyurl.com/zl7vxy9</u>).
- HealthMatters Program. (March 2016). EAGLES Soar Toward Health. *HealthMatters Program Online Newsletter*. Online Newsletter from the HealthMatters Program, 1(2) (<u>https://tinyurl.com/z9pvavr</u>).
- HealthMatters Program. (February 2016). Evaluate your 12-Week HealthMatters Program. *HealthMatters Program Online Newsletter*, 1(1) (https://tinyurl.com/zf7yo9d).

Newsletters/Periodical Interviews/Social Media, cont.

- McCulloh, K.J. & Marks, B. (September 11, 2014). *National Organization of Nurses with Disabilities: Advocating and Educating to Remove Barriers to Education and Employment for People with Disabilities*. Social Security Administration, Ticket to Work Blog Post (https://www.choosework.net/blog-archive/blog-post?post_id=347)
- Edwards, J. (April/May 2013). Game Changers. Nurses With Disabilities Work to Dispel Bias in Health Care. *Insight into Diversity*, *p* 8-10. Retrieved from (www.insightintodiversity.com/).
- Johnson & Johnson NursingNotes. (2010). Enabling a Community of Nurses. Personal Interview.
- Minority Nurse. *Nurses with Disabilities*. (2002). Interview with Ruth Carol. Available on-line at (www.minoritynurse.com/features/nurse_emp/01-27-02h.html).

BOOKS, CHAPTERS, MONOGRAPHS, BRIEF REPORTS

- Marks, B., Sisirak, J., & Heller, T. (in press) Health promotion and people with intellectual disabilities. In V. P., Prasher & M.P. Janicki (Eds.) Physical Health of Adults with Intellectual Disabilities. New York: Springer.
- Sisirak, J., Marks, B., Heller, T., Ronneberg, C., McDonald, K., & Ailey, S. (2016). *People with IDD: Health and wellness for all*. In Critical Issues in Intellectual and Developmental Disabilities: Contemporary Research, Practice, and Policy. AAIDD: Washington, DC.
- Marks, B. & Ailey, S. (2014). White Paper on Inclusion of Students with Disabilities in Nursing Educational Programs for the California Committee on the Employment of People with Disabilities. Chicago, IL. Featured on The American Association of Colleges of Nursing (AACN) website: Accommodating Students with Disabilities (<u>https://tinyurl.com/ov6tlec</u>).
- Sisirak, J. & Marks, B. (2013). Promoting Nutrition across the Lifespan: Person-Centered Ecological Nutrition Framework for People with Intellectual Disabilities, pp. 44-54. In L. Taggart & W. Cousins (Eds), *Health Promotion for People with Intellectual and Developmental Disabilities*. McGraw Hill Education: Maidenhead, Berkshire, UK: Open University Press. ISBN: 13: 978-0-335-24694-3.
- Marks, B. & Sisirak, J. (2013). Community health promotion programmes, pp. 17-30. In L. Taggart & W. Cousins (Eds), *Health Promotion for People with Intellectual and Developmental Disabilities*. McGraw Hill Education: Maidenhead, Berkshire, UK: Open University Press. ISBN: 13: 978-0-335-24694-3.
- Heller, T., Fisher, D., & Marks, B. (2013). Ageing, pp. 138-148. In L. Taggart & W. Cousins (Eds), *Health Promotion for People with IDD*. McGraw Hill Education: Maidenhead, UK: Open University Press. ISBN: 13: 978-0-335-24694-3.
- Marks, B., Sisirak, J., Medlen, J., & Magallanes, E. (2012). *HealthMessagesTM Program: Healthy Lifestyle Coaches Coaching Manual*. Rehabilitation Research and Training Center on Aging with Developmental Disabilities, Chicago, IL.
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PRESENTATIONS

Refereed Paper Presentations (2002-2018) (N=73)

National Paper Presentations (N=52)

<u>Nursing Conferences</u> (N=5): NLN (n=3), Western Institute of Nursing (n=1), and CCNE (n=1);
 <u>Multidisciplinary Health Conferences</u> (N=19): American Public Health Association (APHA) (n=16), Health Literacy Research (n=1), American Physical Therapy Association (n=1); National Council on the Aging and American Society on Aging Joint Conference (n=1); and,
 <u>Disability and Health Conferences</u> (N=28): Coalition for Disability Access in Health Science and Medical Education - 5th Annual Symposium (n=1), American Association on Intellectual and Developmental Disabilities (AAIDD - formerly AAMR) (n=4), American Academy of Developmental Medicine and Dentistry (n=2), Illinois Transition Conference (n=2); QMRP Leadership Conference (n=1), Society for Disability Studies (n=1), Project SEARCH Annual Conference (n=2), RRTCDD/The Arc US *Health and Wellness 2016-2018 Webinar Series* (series co-director; n=10), *HealthMatters ProgramTM*/Project SEARCH 2017-2018 *Employment, Health, and Wellness Webinar Series* (series co-director; n=5)

International Paper Presentations (N=12)

<u>Disability and Health Conference</u>: International Association for the Scientific Study of Intellectual and Developmental Disabilities (n=11) and Multidisciplinary Health Conference: IUHPE World Conference on Health Promotion (n=1)

Summary: Presentations focused on disseminating information related to our "HealthMatters Program Train-the-Trainer Certified Instructor Workshop," along with the need for strategies to build capacity among caregivers and within organizations (n=17). The second most common focus related to our "Health Matters 12-Week Program" and providing evidence supporting the benefits of the "Health Matters: Exercise and Nutrition Health Education Curriculum for Adults with Developmental Disabilities" (n=14). I, and my colleagues presented the "HealthAdvocacy Program" and the need for health professionals to understand health issues for people with disabilities from a social model and promote health advocacy for people with disabilities (n=4). Data from the "HealthMessages Program" was presented, along with the benefits of teaching people with IDD to become Peer Health Coaches (n=3). Four additional presentations presented results from our evaluation of other health promotion programs. Two presentations following the publication of the "Jumping

Through Hoops and Walking on Egg Shells or Discrimination, Hazing, and Abuse of Students with Disabilities?" article was one of the first efforts to present the social model of disability and the need to include students and nurses with disabilities as our peers (n=2).

Refereed Poster and Roundtable Presentations (2002-2016) (N=11)

National Poster/Roundtable Presentations (N=10): <u>Multidisciplinary Health Conferences</u>: APHA (n=5) and <u>Disability and Health Conferences</u>: AAIDD (n=4), Southwest Conference on Disability (n=1) *International Poster/Roundtable Presentations (N=1):*

Multidisciplinary Health Conferences: World AIDS Conference (n=1),

Summary: Several poster presentations provided details of our "Health Matters 12-Week Program" and the theoretical structure of the "Health Matters: Exercise and Nutrition Health Education Curriculum for Adults with Developmental Disabilities" (n=4). Three presentations discussed the framework and process of the "HealthMatters Program Train-the-Trainer Certified Instructor Workshop." I, and my colleagues presented the conceptual framework and the outcomes of "HealthAdvocacy Program" for pediatric residents and the potential impact for children and adolescents with disabilities (n=1). Three additional presentations discussed results from the evaluation of external health promotion programs.

Keynote Presentations (2005-2018) (N=5)

National Keynote Presentations (n=4): International Keynote Presentations (n=1):

Summary: The need to build capacity for caregivers and organizations to achieve healthfriendly services and sustainable health promotion programs for people with IDD was the theme for two Keynote presentations. One Keynote presentation discussed the importance and impact of direct support professionals providing exercise and nutrition health education **Summary, cont.:**

for people with IDD. Another Keynote presentation discussed the importance of teaching health advocacy skills for children and adolescents with disabilities from a social model perspective to a mixed audience of direct support staff, managers, family members, and people with disabilities. A Keynote addressing nursing students and nurses with disabilities provided the opening remarks to a roundtable discussion on developing strategies to support nursing students and health care professionals and remove barriers to success.

Invited International Presentations (2005-2018) (N=7)

Health Promotion and People with IDD

- 1. Toronto, Canada (Annual Conference on Health and Well-Being Sponsored by Academia and NGOs)
- 2. Cairns, Australia and Jinan, Shandong, China (WHO Asia Pacific Emergency and Disaster Nursing Network)
- 3. Kowloon, Hong Kong (International Professional Conference)

4. Mumbai, Maharashtra, India (Collaborative between University and local and national NGO Health Services (e.g., Indian Red Cross).

Summary: Socio-environmental support through community academic partnerships became increasingly recognized as a necessary component for health promotion for people with IDD and a message that resonates in other countries. The presentation with my colleague in Mumbai detailed our preliminary results of our *Feasibility Study* (2004) aimed at advancing nursing education at Bel-Air Hospital. In the 14 years following this study, a College of Nursing was created at Bel-Air Hospital with a four-year baccalaureate and a masters' program in nursing. Additionally, the WHO Asia Pacific Emergency and Disaster Nursing Network presented an opportunity to discuss the inclusion of people with IDD, along with key factors to consider in all disaster training programs.

Invited National Presentations (2005-2018) (N=35)

Health and Health Promotion and People with IDD (n=24) *Students and Nurses with Disabilities* (n=11)

Summary: The need for systematic, cost-effective, time-efficient, and accessible scale-up efforts was a primary topic in many of the national invitational presentations (n=14). Interest in health education for people with IDD across the lifespan continued to grow as more people with IDD live in our communities and have very different expectations based on philosophical changes for people with IDD, along with legal mandates (e.g., IDEA, ADA, ADAAA, OFCCP 7% Rule) that support the rights of people with IDD to live, learn, work, and recreate in our communities). Health, health education, and health promotion is critical to one's success in being able to live, learn, work, and recreate (n=8). As more people benefit from the Americans with Disability Act (ADA) of 1990 and the ADA Amendment Act of 2008, nursing programs increasingly wanted capacity-building programs on best practices to support students with disabilities in nursing education (n=11). Two presentations focused on general health and health promotion and evaluation strategies for people with IDD.

Invited Statewide Presentations (2000-2016) (N=29)

Health Promotion and People with IDD (n=24) *Students and Nurses with Disabilities* (n=5)

Summary: Statewide presentations are often an opportunity to focus on building capacity within states to scale-up health promotion for people with IDD (n=11). Additionally, invitational statewide presentations are an opportunity to present information from our "Health Matters 12-Week Program" for people with IDD and how to implement a sustainable exercise, nutrition, and physical activity program (n=8) for professional organizations. With our statewide scale-up efforts, awareness of our evidence-based and evidence-informed programs is growing and we have started to present on the following: "HealthAlert Program" to discuss the need to observe and report early signs of health changes (n=1); "HealthAdvocacy Program" to promoting health for people with IDD (n=1); and the "HealthMessages Program" to teach people with IDD to become Peer Health Coaches (n=1). Two presentations focused on aging and IDD – an area of increasing interest. Several states with inter-connected community college systems coordinated statewide presentations for best

practices in supporting success among nurses with disabilities (n=5).

Invited Local Presentations (2003-2016) (N=13)

Health and Health Promotion and People with IDD (n=11) *Students and Nurses with Disabilities* (n=2)

Summary: Local invitational presentations are related to practical strategies for teaching people with IDD about health (n=5) and health promotion (n=6) and how to adapt the "Health Matters 12-Week Program" for people with IDD using universal design principles.

EDUCATION AND TEACHING

Invited Presenter: National and International

- University of Illinois (UIC), College of Nursing. Open the Door, Get 'Em a Locker: Building Capacity for Success, 2014-2017.
- University of Lexington. *Health Matters for People with Developmental Disabilities: Promoting Health Advocacy*, 2013-2016.
- UIC, NIOSH Interdisciplinary Educational Resource Center. *Nurses with Disabilities and Cultural Competence: A Research Agenda for Inclusion in Occupational Health*, 2009.
- Women's University, College of Nursing, Mumbai, Maharashtra, India. *Aging and Disability*, 2004.
- Interdisciplinary Health Professionals Training, Institute for Rehabilitation, Ljubljana, Slovenia (Marks, B., Ailey, S.A., & Sisirak, J.). *Health Promotion and Disability Across the Lifespan*, 2002.
- University of Illinois, College of Nursing, Women's Health. *The hidden curriculum relative to disability in women's health curricula*, 2000.
- Lithuania (multiple sites) (Slutas, F., Norr, K., Christiansen, C., & Marks, B.). *Peer* education course for AIDS prevention, 1997.

Community Service: National Organization of Nurses with Disabilities (NOND)

Systems Change

Health Care Professionals with Disabilities Career Trends, Best Practices, and Call-to-Action Policy Roundtable. March 18, 2014, Washington, DC.

Host Organizations: U.S. Department of Labor (DOL)/Office of Disability Employment Policy (ODEP) in collaboration with the National Organization of Nurses with Disabilities (NOND). **Co-Sponsors:** U.S. Department of Labor/Employment and Training Administration (ETA) U.S. Department of Health and Human Services/Health Resources and Services Administration (HRSA).

Alliance Goal: I, and my NOND colleagues recognized the value of establishing a collaborative relationship to promote the inclusion of nursing students with disabilities and the sustained employment of people with disabilities in the healthcare industry. One key activity of our Alliance with ODEP was to development of a co-sponsored roundtable discussion among key

stakeholders to address the intersection between disability employment and the health care industry.

Stakeholders: This full-day event convened more than 40 key opinion leaders from across the country, including employers, Federal and state policymakers/agencies, researchers, academicians, educational administrators, nursing leadership, academia, disability community:

American Association of Colleges of Nursing, American Academy of Nursing, American Association of Community Colleges, Association on Higher Education and Disability (AHEAD), Bon Secours Virginia Health System, California Committee on Employment of People with Disabilities, Department of Justice (DOJ), Employment and Training Administration (ETA), Great Lakes ADA Center, Health Resources and Services Administration (HRSA), Higher Education Recruitment Consortium (HERC), Highmark Health, Job Accommodations Network, National Council of State Boards of Nursing (NCSBN), National Council on Independent Living, National League on Nursing, Rehabilitation Services Administration (RSA), Rochester Institute of Technology/National Technical Institute for the Deaf, U.S. Equal Employment Opportunity Commission (EEOC), WellPoint

Location: U.S. Access Board in Washington, DC.

Role: President of NOND and Panel Member in Session 1 "Driving Access to Post-Secondary Educational Programs in Nursing & Allied Health Professions for Prospective Students with Disabilities and Returning Veterans."

Self-Paced Online Modules

- Marks, B. (7/10). Students with Disabilities: A Paradigm Shift.
- Marks, B. (6/10). Opening Doors for Nursing Students with Disabilities-Building Capacity for Success.
- Evans, B. & Marks, B. (6/10). *How Can They Be Nurses? Apprehension about Nursing Students with Disabilities.*
- Evans, B. & Marks, B. (6/10). Not Able, Terribly Different: Do Nursing Students with Disabilities Need to Be "Fixed?"

Teaching: Community Service Providers

(e.g., Direct Care Workers, RNs, Nutritionists, OTs, PTs, Recreational Therapists, Managers)

- 1. *HealthMatters Program: Train-the-Trainer Certified Instructor Workshop* (2005-2018) (n=100); States (n=33); Organizations (n=150); Certified Instructors (n=2600)
- 2. *HealthMessages Program: Becoming a Peer Health Coach Webinar* (2012-2018) (n=18); States (n=4); Organizations (40)
- 3. *HealthMatters 4Kids Today Counts for Diabetes Prevention* (2013-2018) (n=15); States (n=1); Organizations (35)
- 4. *Getting The Memo for Health Promotion in your Organization* (2013-2018) (n=12); States (n=7); Organizations (n=60).

Teaching: Adults with Intellectual and Developmental Disabilities (IDD)

- October 2008 Present. *HealthMessages Program: Peer-to-Peer Webinar*. Interactive webinar for people with IDD and mentors to increase knowledge and confidence in providing a health messages to peers IDD.
- October 1998 December 2004. *Exercise and Nutrition Health Education*. Taught 12-week health education course for adults with IDD.

PROFESSIONAL ACTIVITIES

Select Government, Private or Professional Society Committees (n=18)

- 1. Asia Pacific Emergency and Disaster Nursing Network (APEDNN), Western Pacific Regional Office (WPRO), Network Member, 2009 present.
- National Organization of Nurses with Disabilities (<u>NOND.org</u>) <u>Advisory Board</u> (2003-2005; 2016-present); <u>Co-Director</u> and <u>Immediate Past President</u>, (July 2014 June 2016); <u>President</u> (July 2005 June 2014); <u>Website Chair</u> (July 2005 June 2016).
- 3. Institutional Review Board Member. Board #2. September, 2005 2016.
- 4. Peer Reviewer. Special Emphasis Panel on the Health and Wellness of People with Disabilities Disability Intervention (CDC-RFA-DD06-004). Office of Public Health Research Centers for Disease Control and Prevention, Atlanta, Georgia, 2006.
- 5. NorthPointe Resources. NorthPointe Resources Auxiliary Board, 2006 2009.
- 6. Women with Disabilities Education Project, Multidisciplinary Team Discussant. Developed health professions curriculum objectives for women with disabilities. Chicago, IL, 2006.
- 7. Equip for Equality Advisory Council, Traumatic Brain Injury Project, 2003 2008.
- 8. Rush University College of Nursing Task Force Member on the Students with Disabilities: Nursing Education and Practice Symposium, 2002 2003.
- 9. Sigma Theta Tau International, Member of Alpha Lambda Chapter. Developed chapter's website in 1997; Member 1995 present.
- 10. American Nurses Association/IL Nurses Association Member, 1989-91; 1999-01; 2014 -.
- 11. Progress Center for Independent Living Director, Forest Park, IL, 1998-2000.
- 12. Cultural Diversity in the Arts Member & Resource Development, Evanston, IL, 2000-01.
- 13. Better Existence with HIV (BEHIV), Director & Program Chair, Evanston, IL, 1997 2000.

Peer Reviewer for Journals

Disability and Health Journal (Editorial Review Board Member)

Additional Journals include: American Nurse Today Health Promotion International Health Promotion Practice Journal of Applied Research in Intellectual Disabilities (JARID Journal of Intellectual & Developmental Disability Journal of Intellectual Disabilities; Journal of Intellectual Disability Research Journal of Nursing Education Journal of Policy and Practice in Intellectual Disabilities Journal of the American Psychiatric Nurses Association (JAPNA) Policy, Politics, & Nursing Practice PLOS ONE Research in Developmental Disabilities

PROFESSIONAL LICENSURES

Illinois:Registered Nurse, License # 041-271247Ohio and Indiana:Registered Nurse, Inactive