

KAREN J. LUKEN
ABBREVIATED VITA

Disability and Health Consultant

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Degrees Earned

MSRA. Recreation Administration, with a concentration in therapeutic recreation, University of North Carolina at Chapel Hill, 1988

B.S. Leisure Studies, with an emphasis in therapeutic recreation, University of Illinois at Champaign-Urbana, 1979

Certificate in Public Health, School of Public Health, UNC-CH, 2003

Professional Experience

Disability and Health Consultant. September 2013-present.

2020-present: consultant to the I/DD Medical Health Home initiative (I/DD MHHI).

2013-2019: Project director for I/DD Medical Health Home initiative that has received financial support from the NC Council on Developmental Disabilities, NC Dept. of Health and Human Services, and Healthy Blue. The I/DD MHHI partners with individuals with I/DD, families, advocates, health care and disability providers, and thought leaders to develop policy, program and practice recommendations that promote integrated, person-centered care that coordinates primary care, behavioral health, specialty care, dental, and long-term services and supports for people with I/DD.

Consultant: Community Bridges Consulting Group, June – November 2022. Care Extender White Paper: The North Carolina Council on Developmental Disabilities (NCCDD) funded Community Bridges to develop a Care Extender White Paper that summarizes the perspectives of families, individuals with I/DD, LME MCOs, DD Providers, policymakers, and healthcare providers AND identifies strategic recommendations to address potential challenges that could impact success.

Consultant, NC AHEC, January 2020 – present. Development of Project ECHO Network-NC.

Consultant, Oral Health Section, NC Division of Public Health, 2019-August 2022. HRSA grant to improve access to community dental care services for children and adults with I/DD.

Advisor, Duke School of Medicine, PCORI funded “Thriving in Transition” grant, 2021 to 2024.

Advisor, UNC School of Pharmacy, PCORI funded “Improving the health of parents and their adolescent and transition-age youth with IDD” grant, 2022 to present.

Advisor, University of North Carolina, TEACCH Program, PCORI funded “Comparing Cognitive-Behavioral Therapy versus Mindfulness-Based Therapy for Autistic Adults” grant, 2023 to present.

Consultant, National Center on Health, Physical Activity and Disability, University of Alabama at Birmingham, 2014-2018. Disability Rehabilitation Research Program addressing Prevention of Obesity Among Youth with Disability.

Consultant, Lurie Institute on Disability Policy, Brandeis University, 2014-2018. Research study entitled *Understanding Pregnancy Outcomes for Women with Intellectual and Developmental Disabilities*.

Project Director, NC Office on Disability and Health, FPG Child Development Institute, University of North Carolina at Chapel Hill, 2002-2013. Programmatic leadership for health promotions initiatives, technical assistance, materials development, and collaboration with partners including NC Division of Public Health, disability and health service and advocacy organizations, and academic programs. Administrative budget management, staff supervision, and grant development.

Associate Director, Center for Recreation and Disability Studies, Dept. of Recreation and Leisure Studies, University of North Carolina at Chapel Hill, 1999 - 2002. Management of grant and contract projects, acquisition of external funding, dissemination of project findings, staff hiring, training, and supervision, liaison with project partners, and academic course instruction. Projects included Supported Retirement for Adults with Developmental Disabilities, Reintegration Through Recreation for Adult with Serious Mental Illness, Peer Advocacy and Education through Recreation and Leadership for Adults with Serious Mental Illness, Promoting Community Inclusion for Adults with Mental Illness and Developmental Disabilities.

Project Coordinator, Center for Recreation and Disability Studies, Dept. of Recreation and Leisure Studies, University of North Carolina at Chapel Hill, 1991 - 1999. Oversight of federal, state, and county demonstration grants and contracts addressing social inclusion needs of persons with disabilities.

Instructor, Dept. of Recreation and Leisure Studies, UNC-CH, 1989- 2002. Academic courses addressing the practice of Therapeutic Recreation.

Therapeutic Recreation Specialist II, University of North Carolina Hospitals, Chapel Hill, 1981-1990. Clinical services for adults and adolescents in acute care psychiatric unit and out-patient Eating Disorders Clinic.

Rehabilitation Therapist, Orange-Person-Chatham Area Program, 1980-81. Psychosocial rehabilitation services for adults with serious mental illness in a community-based adult psychiatric treatment program.

Rehabilitation Technician, Daniel Drake Hospital, Cincinnati, Ohio, 1974-1977. Activity therapy for adults with physical rehabilitation needs.

Selected Presentations, Workshops, Webinars, and Posters (2006- 2023)

Kendall Fields, L., **Luken, K.** *Supported Healthcare Decision-making*, Southern Regional AHEC workshop, Fayetteville and virtual, February, 2024.

Friedlander, K. **Luken, K.** *Mission Possible: Advancing Whole Person Care by Employing People with Lived Experience*. I2i Center for Integration summer conference, Raleigh, June 2023

Friedlander, K. **Luken, K.** *Mission Possible: Advancing Whole Person Care by Employing People with Lived Experience*. NC TIDE, Wilmington, April 2023

Luken, K. Howell, C. *Supporting Families and Healthcare Providers to Provide Quality Care to Persons with Down Syndrome Across the Lifespan*, NC Down Syndrome Alliance annual conference, Burlington, April 2023

Friedlander, K. **Luken, K.** *Mission Possible: Advancing Whole Person Care by Employing People with Lived Experience*. NC Council on Developmental Disabilities, Raleigh. October 2022.

Luken, K. Welcome to didactic workshop and community-based learning clinic. *Increasing capacity of community dental professionals to provide care to children and adults with intellectual and developmental disabilities*, ECU School of Dental Medicine, Greenville, June 2022 and Lumberton, July 2022.

Luken, K. Dreiling, N. *How TEACCH Autism ECHO programs and Family Support ECHO programs promote quality services for children with special healthcare needs and their families*. Commission for Children with Special health Care Needs. Raleigh, NC. February 2021.

Luken, K. *Building Blocks for the Future in Practice, keynote*. Eastern AHEC I/ DD Services Conference, Greenville, NC. October 2020.

Hinton, J., Robinson, M., **Luken, K.** *Things Are Not Always What They Seem to Be: supporting optimal health for individuals with I/DD and co-occurring psychiatric and physical health issues*. Eastern AHEC I/ DD Services Conference, Greenville, NC. October 2020.

Klinger, L., Maslow, G., Christina, R., Erb, K., **Luken, K.** *Connecting Expertise to Communities to Support Comprehensive Care for People with I/DD: Building on North Carolina's Assets*, i2i Center for Integrative Health webinar, June 2020

Luken, K. *Promoting Person-Centered Care within an Inclusive, Integrated System of Care for People with Developmental Disabilities*. Georgia Learning Collaborative for DD, Savannah, GA. December 2019.

Luken, K., Howard, L. *Improving the Oral Health of People with Intellectual and Developmental Disabilities*, North Carolina Council on Developmental Disabilities, Cary, NC. November 2019.

Luken, K. Erb, K. *Supporting Integrated Care for People with Intellectual and Developmental Disabilities: Opportunities for Impact within the Tailored Plan*, NC DHHS Chief Medical Officers of the LME MCOs, Raleigh, NC. November 2019.

Luken, K., Stephens, R. *Meeting the Oral Health Needs of Diverse Populations*, NC Community Health Center Association meeting of the dental directors, Cary, NC. November 2019.

Valdez, A. **Luken, K.** *Improving Access to Dental Care for Children and Adults with Intellectual and Developmental Disabilities*, Asheville, October 2019

Luken, K. Eaker, K., **Friedlander, K.**, Ingram, D. *Jazz It Up! Building on Our Potential*, National Association of Council on Developmental Disabilities, New Orleans, LA. July 2019.

Luken, K. *The Role of Person-Centered Principles and Practice in Promoting Health and Life Long Integrated Care*, Turning Point Services annual staff meeting, Morganton, NC, June 2019.

Luken, K., Maslow, G., Baker, J. *Providing Integrated Health Supports to Children with Intellectual and Developmental Disabilities and Their Families*, NC START conference, Raleigh, NC, April 2019.

Luken, K. *Building a Person-Centered and Integrated System of Care for People with Intellectual and Developmental Disabilities*, Eastern AHEC Developmental Disabilities Conference, Greenville NC, March 2019.

Luken, K. *Health, Person-Centered Living & Individualized Supports: What's the Connection*, Webinar sponsored by Vaya Health, NC Council on Developmental Disabilities, and Money Follows the Person, November 2018.

Luken, K. and Eaker, K. *Family Support: an overlooked asset that can promote integration and innovation in diverse healthcare settings*, MAHEC Peer Support conference, Asheville, NC, October 2018.

Boynton, J. and **Luken, K.** *Embedding a Whole Person Approach into the Emerging System of I/DD Services*, i2i Center for Integrative Health spring policy forum, Raleigh, June 2018.

Maslow, G. Baker, J. **Luken, K.** *Providing Integrated Health Support to Children with Intellectual and Developmental Disabilities*, START National Training Institute, Boston, MA, May 2018.

Luken, K. *Building the Foundation for Person-Centered Health Care and Quality of Life for People with Developmental Disabilities*, Webinar sponsored by Money Follows the Person, NC DHHS, April 2018.

Luken, K. *The Future of Managed Care in NC*, facilitated panel, The Arc of NC pre-conference, Winston Salem, NC, March 2018

Luken, K. Eaker, K., Kirkland, D. *Putting the Pieces Together for a Successful Transition from Pediatric to Adult Health Care*, Family Support Network Program Transition Fair, Asheville, NC, November 2017.

Luken, K. *Embracing the Challenges of Integrated Care for People with Intellectual and Developmental Disabilities*. NC Providers Council annual conference, Greensboro, NC. September 2017.

Luken, K. *Integrated, Collaborative Care for People with Disabilities: how can it offer help, hope, and a voice for people with brain injury and their families*. NC Brain Injury Advisory Council, Raleigh, NC. September 2017.

Luken, K. *Integrated, Collaborative Care for Children and Adults with Intellectual and other Developmental Disabilities*, Buncombe Children's Collaborative, Asheville NC, September 2017.

Luken, K. *Promoting Integrated, Collaborative Care for People with Developmental Disabilities*, Metrolina DD Providers, Charlotte, NC, June 2017.

Luken, K. *A Systems Change Approach to Person-Centered Collaborative Care for People with Developmental Disabilities*, American Association of Intellectual and Developmental Disabilities annual conference poster session, Hartford, CT. June 2017

O'Neal, D. Thomas, E. **Luken, K.** *What the Health Are We Doing About Wellness*. START National Training Institute, Rye Brook, NY. April 2017.

McKee, J, Charlot, L. **Luken, K.** *Best Practices for Medication Management for Children, Adults and Seniors with Intellectual and Developmental Disabilities*. Clinical Updates Conference, Raleigh, March 2107.

Luken, K., Hinton, J., Erb, K. *Facilitated Case Discussion*, Community Care of North Carolina workshops, Wilmington, Charlotte, Raleigh, Winston Salem, NC. March-April 2017.

Luken, K. Sherri Siegel. *Collaborative Care for People with Developmental Disabilities*, East Carolina University Medical and Family Therapy doctoral class, Greenville, NC. February 2017.

Luken, K. Bowe, C, Hinton, J. Eaker, K. *North Carolina's Path Toward Collaborative Care for People with Developmental Disabilities*. Collaborative Family Healthcare Association conference, Charlotte, NC. October 2016.

Luken, K. *Whole Person Care for People with Intellectual and Developmental Disabilities: collaboration, innovation, and change*. 2016 Clinical Conference on Quality and Chronic Disease, Durham, NC. April 2016.

Rives, P; Martin, C, Carter, C, Izor, D, Cox, R. Flemming, E. **Luken, K.** *Whole Person Care: Raising the Bar on Inter- Disciplinary Collaboration*, NC Council of Community MH-DD-SAS programs, Pinehurst, NC. December 2015

Luken, K. *North Carolina's Path Toward Medical Health Homes for People with Developmental Disabilities: What We Have Learned is Needed to Transform Care*, MAHEC Transforming Care, Asheville, NC. October 2105.

Luken, K. *The Critical Role of Families, Community Providers, and Partners in Providing Patient-Centered, Collaborative Care*, MAHEC Transforming Care, Asheville, October 2105.

Carter, C and **Luken, K.** *North Carolina's Path toward Medical Health Homes for People with Developmental Disabilities: The Need for Collaboration, Coordination, and Community*. American Academy of Developmental Medicine and Dentistry, Los Angeles, July 2015.

Luken, K. *Collaboration, Coordination, and Community: North Carolina's Path toward Integrated Care for People with I-D*, NC Council of Community MH/DD/SA Programs, Partners MCO LME. Gastonia, June 2015.

Luken, K. *Medical Health Homes for People with Intellectual and Developmental Disabilities*, Autism Society of NC Chapter Dinner, Charlotte, NC. April 2015.

Luken, K. *Making Medical Homes Work for Everyone*, First in Families NC Summit, Durham, NC, March 2015.

King, B., Hinton, J., **Luken, K.** Crane, S., Carter, C., Burnette, R., Hedrick, S. *A Population Health Approach to Healthcare for the People with I/DD: Improving Outcomes through Collaboration, Data and Outreach*. NC Council of Community Programs, Pinehurst, NC, December 2014.

Luken, K., Kluttz-Hile, C. *Integrating Primary Care and Disability Services for People with Intellectual and Developmental Disabilities: realities and opportunities*. Eastern AHEC Developmental Disabilities conference, Greenville, NC, October 2014

Luken, K. *Integrated Care for People with /IDD*. The Arc of NC annual conference, Cary, NC, October 2014

Luken, K. *Integrated Care for People with IDD: what can and should North Carolina do?* Carolina Institute on Developmental Disabilities, Carrboro, NC. May 2014.

Luken, K. Hinton, J. *Medical Health Homes for People with IDD: what does North Carolina Need?* Clinical Update conference, Raleigh, NC. February 2014

Mackey, C. **Luken, K.**, Simmons, J. *Ensuring Access to Primary Care for Patients with Disabilities*. Blue Ridge Health Center. December 2013

Luken, K. *Women Be Healthy workshop: training community facilitators*. Chapel Hill, November 2013

Luken, K. *Making Ensuring Access to Primary Care for Patients with Disabilities*, Community Health Center Association conference, Charlotte, NC. June 2013

Luken, K. Mackey, C. Rauworth, A. *Ensuring Women with Disabilities Receive Breast and Cervical Cancer Screening*. NC WiseWoman Program, Raleigh, NC. June 2013

Luken, K. *The Fundamental Elements of Accessibility: promoting equitable access to services for victims with disabilities.* NC Victims Assistance Network Justice Academy. Raleigh, NC. March 2013

Fisher, K., Williams, G., **Luken, K.**, Parish, S.L., Swaine, J.G., & Dickens, P. *Making a difference in the lives of women with IDD: Moving research findings about breast and cervical cancer screening into the real world.* Poster presented at the annual conference of the American Association on Intellectual & Developmental Disabilities. Charlotte, NC. June 2012

Fisher, K., Williams, G., **Luken, K.**, Swaine, J.G., & Parish, S. *Researchers and women with intellectual disabilities: Partnerships to promote cervical and breast cancer screening.* Poster presented at the annual conference of the American Association on Intellectual & Developmental Disabilities. Charlotte, NC. June 2012

Swaine, J.G. **Luken, K.** & Parish, S.L. *An empowerment-based method for recruiting women with intellectual disabilities to participate in health promotion research.* Poster presented at the annual conference of the American Association on Intellectual & Developmental Disabilities. Charlotte, NC. June 2012

Luken, K. *Women Be Healthy.* Planned Parenthood, Wilmington, NC, August 2011.

Luken, K. Dickens, P., Jones, M. *Supporting People to Get Healthier Lives through Person Centered Practices,* Person Centered Practices, Chapel Hill, NC. May 2011

Hiss, B Mackey, C., Madrigal, J., **Luken, K.** *Inclusive Fitness Training Workshop: Exercise Programming for Individuals with disabilities and Activity limitations,* Greater Charlotte YMCA. March 2011

Luken, K. Swaine, J.G, Dickens, P., Wright, G. *Women Be Healthy: Improving Cervical and Breast Cancer Screening for Women with Developmental Disabilities,* FPG CDI Seminar, November 2010

Luken, K. NC Governor's Conference on Aging, Removing Barriers to Community-based Dental Services, poster presentation. Winston Salem, NC. October 2010

Reinhartsen, D.B., Pretzel, R.E, Kelsey, K., Greenleaf Bailey, R., **Luken, K.** Fernandez, M., Simmons, A. & Qadura, T. *Analysis of National Core Indicators Data: does healthcare vary according to type of funding?* AUCD poster presentation. October 2010

Luken, K. Wright, G. Dickens, P & Mackey, C. *Let's Talk About Health,* The Arc of NC conference. September 2010.

Luken, K. Mackey, C. *Promoting Inclusive Health and Fitness Opportunities for People with Disabilities,* CDC Obesity Prevention Course, Round table discussion. Chapel Hill, NC. August 2010.

Luken, K. *Overview of the NC Plan to Promote the Health of People with Disabilities*, NC Immunization Coalition. June 2010

Hiss, B Mackey, C., **Luken, K.**, *Inclusive Fitness Training Workshop: Exercise Programming for Individuals with Disabilities and Activity Limitations*, Richmond, VA. March 2010

Luken, K. Wright, G. Dickens, P, Mackey, C. *There's Nothing More important than Your Health*, The Arc of NC conference. September 2009.

Luken, K. *NC Office on Disability and Health, Livable Communities panel*, Annual CDC State Grantees meeting, New Orleans. April 2009

Luken, K. *NC Office on Disability and Health, Surveillance Panel*, Annual State Grantees meeting, New Orleans. April 2009.

Fernandez, M, Greenleaf, R., **Luken, K.** Development of the North Carolina and the NCI Surveys brochure, HSRI webinar. March 2009

Mosley, C. Taub, S. **Luken, K.** Thompson, S. *Exploring Disability Data sets: Overview of Core Indicators Project. The Role of Public Policy in Addressing the Health-Related Needs of Individuals with Disabilities*, AUCD webinar. October 2008.

Luken, K., *The Role of Public Policy in Addressing the Health-Related Needs of Individuals with Disabilities*, UNC-CH School of Nursing. Fall 2008

Luken, K. *Emergency Preparedness: ensuring the needs of persons with disabilities are addressed*. Orange County Health Dept. Community meeting. September 2008

Luken, K. *Using Data to Address the Health Needs of Persons with Disabilities*, Montana Rehabilitation and Research Center. September 2008

Dickens, P., **Luken, K.** *Women Be Healthy Workshop*, Montana Disability and Health Program, Missoula, Montana. September 2008

Dickens, P., **Luken, K.** *Building Community Partnerships to Support Women Be Healthy Implementation*, Montana. September 2008

Luken, K. Mackey, C. (2008) *Improving Access: Ensuring Opportunity for Seniors with Disabilities*, NC Division of Aging and Adult Services Senior Management Training Institute, Clemmons, NC. April 2008.

Luken, K. *Promoting the Health of Women with Intellectual Disabilities*. Healthy Women, Healthy Babes conference, AHEC, Greensboro. NC. March 2008.

Moss, K. **Luken, K.** *The Importance of Healthcare Advocacy. Best Practices in Services and Supports for Persons with Developmental Disabilities.* High Point, NC. March 2008

Luken, K. *Reaching New Heights in Quality Health Care, Best Practices in Services and Supports for Persons with Developmental Disabilities.* High Point, NC. March 2008

Luken, K. Dickens, P. Access for All: Patients with Disabilities. Medical Society of NC. Charlotte, NC. June 2007

Moss, K. **Luken, K.** *Healthcare and Safety Planning: a prerequisite for living in the community.* NC Council for Community Programs conference. 2007

Luken, K. *Innovative and Non-traditional Partnerships in the Development of Health and Wellness Program for Persons with Disabilities.* NCBDDD State Grantee & External Partner Annual Meeting, Ames, Iowa. June 2006

Mackey, C. **Luken, K.** *Emergency Preparedness, Best Practices in Community Supports and Services,* Greensboro, NC. April 2006

Publications (2006-2012)

Publications/Journal articles

Rimmer, J. H, Vanderbom, K.A., Bandini, L.G., Drum, C.E. **Luken, K.**, Suarez-Balcazar, Y., Graham, I.D. (2014). GRAIDs: a framework for closing the gap in the availability of health promotion programs and interventions for people with disabilities, *Implementation Science* 2014, 9:100 doi:10.1186/s13012-014-0100-5

Swaine, J.G., Parish, S.L., **Luken, K.**, Son, E., & Dickens, P. (2014). Testing of an intervention to improve knowledge of women with intellectual disabilities about breast and cervical cancer. *Journal of Intellectual Disability Research.* Volume 58, Issue 7, pages 651–663, July 2014

Parish, S.L., Swaine, J.G., Son, E., & **Luken, K.** (2013). Determinants of cervical cancer screening among women with intellectual disabilities: Longitudinal evidence from medical record data. *Public Health Reports,* 128, 519-526.

Swaine, J.G., Parish, S.L., Subharati Ghosh, **Luken, K.** & Wright, G. (2013). Obtaining medical records for women with developmental disabilities in a community-based health promotion intervention. *Journal of Policy and Practice in Intellectual Disabilities.* Volume 10, Issue 1, pages 54–61.

Parish, S.L., Swaine, J.G., Dababnah, S., & **Luken, K.** (2013). Family Caregivers' Perspectives on Barriers and Facilitators of Cervical and Breast Cancer Screening for Women with Intellectual Disabilities. *Journal of Intellectual and Developmental Disabilities,* vol. 51, no. 1m 62-73. DOI: 10.1352/1934-9556-51.01.062.

Parish, S.L., Swaine, J.G., Son, E. & **Luken, K.** (2013). Receipt of mammography among women with intellectual disabilities: Medical record data indicate substantial disparities for African American women. *Journal of Disability and Health*, Jan;6(1):36-42. doi: 10.1016/j.dhjo.2012.08.004. Epub 2012 Sep 28.

Swaine, J.G., **Parish, S.L.**, & Luken, K. (2013). Breast and cervical cancer screening for women with intellectual disabilities. *Health & Social Work*, 38, 183-186.

Son, E., **Parish, S.L.**, Swaine, J.G., & **Luken, K.** (2013). Accuracy of reporting receipt of cervical and breast cancer screening among women with intellectual and developmental disabilities. *American Journal of Intellectual and Developmental Disabilities*, 118, 327-336.

Herrick, H. **Luken, K.** (2012) The Burden of Heart Disease Among North Carolina Adults with Disabilities. *N C Med J.*;73 (6):499-503.

Parish, S.L., Swaine, J.G., Son, E. & **Luken, K.** (2012) Receipt of mammography among women with intellectual disabilities: Medical record data indicate substantial disparities for African American women. *Disability and Health Journal*. 6(1):36-42. doi: 10.1016/j.dhjo.2012.08.004.

Parish, S.L., Swaine, J.G., **Luken, K.**, Rose, R.A., & Dababnah, S. (2012). Cervical and breast cancer screening knowledge of women with developmental disabilities. *Intellectual & Developmental Disabilities*.

Parish, S.L., Rose, R.A., Swaine, J.G., **Luken, K.**, & O'Hare, L. (2012). Cancer screening Knowledge changes: Results from a randomized control trial of women with developmental disabilities. *Research on Social Work Practice*, 22, 43-53. [DOI: 10.1177/1049731511415550]

Jarman, M.P., Bowling J.M., Dickens P., **Luken K.**, Yankaskas, B.C. (2012) Factors facilitating acceptable mammography services for women with disabilities. *Women's Health Issue*. 22(5):e421-8. doi: 10.1016/j.whi.2012.06.002. Epub 2012 Jul 17.

Dickens, P., **Luken, K.**, Parish, S.L., & Swaine, J.G. (2011). *Women Be Healthy 2: A curriculum to increase cervical and breast cancer screening rates of women with intellectual and developmental disabilities*. Chapel Hill, NC: North Carolina Office on Disability & Health.

Swaine, J. G., Parish, S.L., **Luken, K.**, & Atkins, L. (2011). Recruitment and consent of women with intellectual disabilities in research studies. *Journal of Intellectual Disability Research*, 55, part 5; 474–483. [DOI: 10.1111/j.1365-2788.2011.01399.x]

Miles DR, Steiner MJ, **Luken K**, Sanderson MR, Coyne-Beasley T, Herrick H, Mizelle E, Ford CA. Health and Educational Status of Children Raised by a Caregiver with Disability, *Disability and Health Journal*, Jul;4(3):185-91. doi:10.1016/j.dhjo.2011.03.004

Yankaskas, B. C, Dickens, P., Bowling, J. M., Jarman, M. P., **Luken, K.**, Salisbury, K., Halladay,

J., & Lorenz, C. (2009). Barriers to adherence to screening mammography for women with disabilities. *American Journal of Public Health*, 99, 12.

Hodges, J.S., & **Luken, K.** (2006). Stakeholders' perceptions of planning needs to support retirement choices by persons with developmental disabilities. *Therapeutic Recreation Journal*, 40, 94-106.

Policy Briefs, Monographs, & Other Reports

Friedlander, K. **Luken, K.** Mission Possible: Advancing Whole Person Care by Employing People with IDD and Family Members as Care Extenders (2022). Community Bridges Consulting Group. <https://www.cb-cg.com/care-extenders.html#TheReport>

Luken, K. People Living with Intellectual and Developmental Disabilities Deserve Quality Dental Care, The Road to Oral Health Equity in North Carolina (2018). NC DHHS, Office of Minority Health and Health Disparities and NC Public Health.
<https://publichealth.nc.gov/oralhealth/docs/OralHealth-Newsletter-092418-WEB.pdf>

Dental Care for People with Developmental Disabilities, Innovations in Oral HealthCare, Programs, Projects, and Strategies for Improving Access to Quality Oral Health Care in North Carolina, (2017). NC Oral Health Collaborative, a program of the Foundation for Health Leadership and Innovation.
https://drive.google.com/file/d/0B9yd_cH0xazsaU9iZnVjWDkzMkU/view

Swaine, J.G., Parish, S.L., **Luken, K.**, & Dickens, P. (2012, February). *Feasibility and acceptability of Women Be Healthy 2: An intervention to improve cancer screenings*. Waltham, MA. Lurie Institute on Disability Policy, Brandeis University.
<http://lurie.brandeis.edu/pdfs/Feasibility%20and%20Acceptability%20of%20WBH21.pdf>

Swaine, J.G., Parish, S.L., & **Luken, K.** (2012, January). *Health screenings for women with developmental disabilities: Notes for social workers and case managers*. Waltham, MA. Lurie Institute on Disability Policy, Brandeis University.
<http://lurie.brandeis.edu/pdfs/healthscreening%20for%20women%20with%20DD.pdf>

Herrick H, **Luken K**, Dickens P. *Women with Disabilities and Heart Disease*. North Carolina BRFSS Surveillance Update, No. 5. Raleigh, NC, July 2011. DHHS, Chronic Disease and Injury Section, State Center for Health Statistics, North Carolina Office on Disability and Health, University of North Carolina, Chapel Hill.

Swaine, J.G., Parish, S.L., & **Luken, K.** (2011, June). *Research: A guide for self-advocates with disabilities*. Waltham, MA. Lurie Institute on Disability Policy, Brandeis University.
<http://lurie.brandeis.edu/pdfs/research-guide.pdf>

Swaine, J.G., Parish, S.L., & **Luken, K.** (2011, June). *Increasing cervical and breast cancer screening rates for women with developmental disabilities: Interim report to the North Carolina*

Division of Mental Health, Developmental Disabilities & Substance Abuse Services. Chapel Hill, North Carolina: University of North Carolina School of Social Work.

Parish, S.L., Swaine, J.G., **Luken, K.**, Rose, R.A., Dababnah, S., & Fichtenbaum, R. (2011, June). *Increased knowledge of breast and cervical cancer screening needed among women with developmental disabilities.* Waltham, MA: Lurie Institute for Disability Policy, Brandeis University. <http://lurie.brandeis.edu/pdfs/pb3-womens-knowledge.pdf>

Dickens, P., **Luken, K.** Dababanah, Parish, S.L. (2011, June). *Recommended Health Screenings for Women with Disabilities.* Waltham, MA: Lurie Institute for Disability Policy, Brandeis University. <http://lurie.brandeis.edu/pdfs/Prevention%20Guidelines%20FINAL.pdf>

Parish, S.L., Swaine, J.G., **Luken, K.**, & Moss, K. (2010, July). *Improving cervical and breast cancer screening for women with developmental disabilities in North Carolina.* Report for the North Carolina Division of Mental Health, Developmental Disabilities & Substance Abuse Services. Chapel Hill, North Carolina: School of Social Work, University of North Carolina at Chapel Hill.

NC Dept. of Health and Human Services, Division of Mental Health, Developmental Disabilities, Substance Abuse Services, Carolina Institute of Developmental Disabilities and NCDOH (2010). North Carolina and the National Core Indicators Survey brochure.

NC Dept. of Health and Human Services, Division of Public Health, State Center for Health Statistics, Children Raised by a Caregiver with a Disability: North Carolina (2010). Fact Sheet posted at <http://www.schs.state.nc.dhhs.gov/champ>

Professional Service (2005-present)

NC Institute of Medicine, Oral Health Transformation Task Force, 2023.

Special Care Dentistry Advisory Group, NC Division of Public Health, Women's and Children's Health, 2014 – 2024.

Practice Improvement Collaborative, NC Division of Mental Health, Developmental Disabilities, Substance Abuse Services, 2005- 2019

First in Families NC, Board of Directors, 2015– 2018

NC Oral Health Collaborative, 2014-2017

NC Integrated Care Committee, 2014 – 2018

The Arc, HealthMeet initiative, National Advisory Committee member, 2012- 2013

NC Autism Alliance, 2008 – 2014

First in Families NC, Coming of Age Task Force addressing aging and developmental disabilities, 2012- 2014

Arc of NC, NASI-funded vulnerable communities Social Security grant, Advisory Committee member, 2010-2011

FPG Child Development Initiative Strategic Plan, Health Committee, co-chair, 2009-2013.

NC Immunization Coalition, 2006 - 2013

Special Care Dentistry Advisory Work Group convened by the NC Division of Public Health, 2009-2010.

NC Institute of Medicine, Developmental Disabilities and Transition Task Force, 2008 - 2009.

NC Council for Allied Health, Chair, 2007-2009.

American College of Sports Medicine, technical work group for development of a specialty certification on inclusive fitness for personal fitness trainers, 2007

American Association of Disability and Health technical assistance for local Susan G. Komen grant to address access to breast healthcare services for women with disabilities, 2007.

NC Council on Developmental Disabilities, technical assistance for recipients of Access to Healthcare grants, 2004-2007.

Center for Women's Health Research, UNC-CH Advisory group for Women's Report Card, 2007

Board of Directors, XDS Inc., not-for-profit agency serving individuals with co-occurring disabilities living in the community, 2004 – 2008

Advisor, NC Association of Self Advocates, 2004- 2008

Invited reviewer, CDC Extra-mural research grants panel, 2016, 2006

Awards

Distinguished Leadership Service Award, NC Council on Developmental Disabilities, November 2019

Journal Reviewer

Journal of Intellectual and Developmental Disabilities

Journal of Trauma, Violence, & Abuse

Journal of Disability and Health

Journal of Psycho-Oncology

Professional and Student Mentoring

UNC School of Public Health, MPH practicum, Project ECHO Network Needs Assessment, summer 2023.

NC Council on Developmental Disabilities, Advancing Strong Leaders, 2015-2016

UNC-CH School of Public Health, Student Service-Learning Team, Program Assessment class, fall 2014, Access to Health Care infographics

NC Council on DD Advanced Leadership mentorship program, 2013-2014

UNC-CH School of Public Health, School of Social Work graduate internship, fall 2013

University of South Carolina School of Public Health, graduate internship, spring 2013

UNC-CH School of Public Health, Student Service-Learning Team, Program Assessment class, fall 2014. Access to and Continuity of Health Care for People with Developmental Disabilities

UNC-CH School of Public Health, Student Service-Learning Team, Program Assessment class, fall 2013. Accessibility of Farmers' Markets

UNC-CH School of Public Health, Student Service-Learning Team Program Assessment class, spring 2012. Oral Health and People with Disabilities

UNC-CH School of Public Health, Student Service-Learning team, Program Assessment class, spring 2011, Public Health Surveillance Systems and Disability

UNC-CH APPLES intern, spring 2010.

UNC-CH School of Social Work intern, fall 2008 – spring 2009.

Washington University OT PhD. student internship, summer 2007