#### **CURRICULUM VITAE**

# DORA M RAYMAKER OCTOBER 2020

#### Education

Ph.D.	2015	Systems Science, Portland State University
M.S.	2009	Systems Science, Portland State University
Graduate Certificate	2007	Computer Modeling and Simulation, Portland State University
Graduate Certificate B.F.A.	2007 1995	Computational Intelligence, Portland State University Painting, Maine College of Art

## **Employment**

- Research Assistant Professor, Portland State University, 2016-current
- Research Associate, Portland State University, 2012-2016
- Web Developer, self-employed, 2006-2015
- Project Director, Autistic Self-Advocacy Network, 2009-2012
- Senior Research Assistant, Oregon Health & Science University, 2009-2012
- Steering Committee Member, University of Montana Rural Research Institute, 2009-2013
- Autism Issues Blogger, Change.org, 2008-2009
- Intranet Specialist, XO Communications Interactive Division, 1995-2006

# **Dissertation**

Intersections of Critical Systems Thinking and Community Based Participatory Research in Developing a Web Site for Autistic Adults, 2015, Chair: Wayne Wakeland; Co-Chair: Christina Nicolaidis

# **Refereed Publications or Other Creative Achievements**

# **Chapters**

**Raymaker, D.M.** (2020). *Shifting the System: AASPIRE and the Loom of Science and Activism*. In S. Kapp (Ed.). Autistic Activism and the Neurodiversity Movement (ch.10) Singapore: Palgrave Macmillan. ISBN 978-981-13-8437-0

McDonald, K, **Raymaker, D.M.,** Gibbons, C. (2016). *A call to consciousness: Community psychology and disability*. In M. Bond, C. Keys, I. Serrano-Garcia (Eds.). American Psychological Association Handbook of Community Psychology (ch.20). Washington, DC: American Psychological Association.

Nicolaidis, C., **Raymaker, D.M.** (2015). *Community based participatory research with communities defined by race, ethnicity, and disability: Translating theory to practice.* In Bradbury, Ed. The SAGE Handbook of Action Research (ch.16). SAGE.

**Raymaker, D.M.,** Nicolaidis, C. (2013). *Participatory research with autistic communities: Shifting the system.* In Davidson, J., Orsini, M. (eds). Worlds of Autism: Across the Spectrum of Neurological Difference (ch.7). University of Minnesota Press.

#### Peer Reviewed Articles

Nicolaidis, C., Zhen, K.Y., **Raymaker, D.M.,** Lee, J., Kapp, S.K., Croen, L.A., Urbanowicz, A., Maslak, J., Scharer, M., and AASPIRE (2020). *Psychometric testing of patient-reported instruments to assess healthcare interventions for autistic adults*. Autism. (in press)

Nicolaidis, C., Schnider, G., Lee, J., **Raymaker, D.M**., Kapp, S.K., Croen, L., Urbanowicz, A., Maslak, J., and AASPIRE. (2020) *Short Report: Development and psychometric testing of the AASPIRE Adult Autism Healthcare Provider Self-Efficacy Scale*. Autism. Published online ahead of print. DOI 10.1177/1362361320949734

**Raymaker, D.M.**, Teo, A.R., Steckler, N., Lentz, B., Scharer, M., Delos Santos, A., Kapp, S., Hunter, M., Joyce, A., Nicolaidis, C. (2020) "Having all of your internal resources exhausted beyond measure and being left with no clean-up crew:" Defining autistic burnout. Autism in Adulthood. Published online ahead of print. DOI 10.1089/aut.2019.0079

**Raymaker, D.M.**, Sale T., Rija M., Buekea, N., Caruso, N., Melton, R., Cohrs, N., Gould, V., Wall, C., Scharer, M. (2020) *EASA Connections: Community-based participatory research to develop a peer-based early psychosis web resource with young adults*. Progress in Community Health Partnerships. (in press)

Nicolaidis, C., **Raymaker, D.M.,** McDonald, K.E., Lund, E., Leotti, S., Kapp, S., Katz, M., Beers, L.M., Kripke, C., Maslak, J., Hunter, M., Zhen, K. (2020) *Creating accessible survey instruments for use with autistic adults and people with other intellectual and developmental disabilities: lessons learned and recommendations. Autism in Adulthood. 2(1):61-76. DOI 10.1089/aut.2019.0074* 

Nicolaidis, C., **Raymaker, D.M.**, Kapp, S.K., Baggs, E., Ashkenazy, E., McDonald, K., Weiner, M., Maslak, J., Hunter, M. (2019) *AASPIRE Practice-Based Guidelines for the Inclusion of Autistic Adults in Research as Co-Researchers and Study Participants*. Autism. 23(8):2007-2019. DOI 10.1177/1362361319830523

**Raymaker, D.M.**, Kapp, S.K., McDonald, K.E., Weiner, M., Ashkenazy, E., Nicolaidis, C. (2019). *Development of the AASPIRE Web Accessibility Guidelines for autistic web users*. Autism in Adulthood. 1(2):146-157. DOI 10.1089/aut.2018.0020

Hughes, R. B., Robinson-Whelen, S., **Raymaker, D.M.**, Lund, E. M., Oschwald, M. M., Katz, M., Starr, A., Ashkenazy, E., Powers, L. E., & Nicolaidis, C., and the Partnering with People with

Disabilities to Address Violence Consortium (2019). *The relation of abuse to physical and psychological health in adults with developmental disabilities*. Disability and Health Journal. 12(2):227-234. DOI 10.1016/j.dhjo.2018.09.007

Raymaker, D.M., McDonald, K., Ashkenazy, E., Gerrity, M., Baggs, A.M., Kripke, C., Hourston, S., Nicolaidis, C. (2017) *Barriers to healthcare: Instrument development and comparison between autistic adults and adults with and without other disabilities.* Autism: The International Journal of Research and Practice. 21(8):972-984. DOI 10.1177/1362361316661261

**Raymaker, D.M.** (2017) *Reflections of a community based participatory researcher from the intersection of disability advocacy, engineering, and the academy*. Action Research. 15(3):258-75. DOI 10.1177/1476750316636669

Nicoladis, C., **Raymaker, D.M.**, McDonald, K., Kapp, S., Weiner, M., Ashkenazy, E., Gerrity, M., Kripke, C., Platt, L., Baggs, A. (2016). *The development and evaluation of an online healthcare toolkit for autistic adults and their providers*. Journal of General Internal Medicine. (10):1180-1189. DOI 10.1007/s11606-016-3763-6

**Raymaker, D.M.** (2016). *Intersections of critical systems thinking and community based participatory research*. Systemic Practice and Action Research. 29(5):405-23. DOI 10.1007/s11213-016-9376-5

Nicolaidis, C., **Raymaker, D.M.**, Ashkenazy, E. McDonald, K., Boisclair, W.C., Baggs, A.E.V., Kapp, S., Weiner, M., Dern, S. (2015). "Respect the way I need to communicate with you": Healthcare experiences of adults on the autism spectrum. Autism: The International Journal of Research and Practice. 19(7): 824–831.

Nicolaidis, C., Kripke, C.C., **Raymaker, D.M.** (2014). *Primary care for adults on the autism spectrum.* Medical Clinics of North America. 98;1169-1191.

Nicolaidis, C., **Raymaker, D.M.**, Katz, M., Oshwald, M., Goe, R., Leotti, S., Grantham, L., Plourde, E., Salomon, J. Hughes, L., Powers, L. (2015). *Participatory research to adapt measures of health and interpersonal violence for use by people with developmental disabilities*. Progress in Community Health Partnerships: Research, Education, and Action. 9(2);157-170.

Oschwald M.L., Leotti, S., **Raymaker, D.M.**, Katz,M, Goe, R, Harviston, M, Wallington, A, Howard, L, Beers, L, Nicolaidis, C, Robinson-Whelen, S., Hughes, R.B., Powers, L.E.; and the Partnering with People with Disabilities to Address Violence Consortium. (2014). *Development of an audio-computer assisted self-interview to investigate violence and health in the lives of people with developmental disabilities*. Disability and Health Journal. 7(3);292-301.

**Raymaker, D.M.**, McDonald, K. (2013). *Paradigm shifts in disability and health: Towards more ethical public health research*. American Journal of Public Health: December 2013, 103(12):2165-2173. Both authors contributed equally to this manuscript.

Nicolaidis, C., **Raymaker, D.M.**, McDonald, K., Dern, S., Boisclair, W.C., Ashkenazy, E., Baggs, A. (2013) *Comparison of healthcare experiences in autistic and non-autistic adults: A cross-sectional online survey facilitated by an academic-community partnership*. Journal of General Internal Medicine. 28(6);761-769.

Nicolaidis, C., Wahab, S., Trimble, J., Mejia, A., Mitchell, S.R., **Raymaker, D.M.**, Thomas, M.J., Timmons, V., Waters, A.S. (2013). *The Interconnections Project: Development and evaluation of a community-based depression program for African-American violence survivors*. Journal of General Internal Medicine. 28(4);530-538.

Wahab, S., Trimble, J., Mejia, A., Mitchell, S.R., Thomas, M.J., Timmons, V., Waters, A.S., **Raymaker, D.M.,** Nicolaidis, C. (2012) *Motivational Interviewing at the intersections of depression and intimate partner violence among African American women. Journal of Evidence Based Social Work.* 11(3), 291-303.

Nicolaidis, C., **Raymaker, D.M.,** McDonald, K., Dern, S., Ashkenazy, E., Boisclair, C., Robertson, S., Baggs, A. (2011) *Collaboration strategies in non-traditional CBPR partnerships: lessons learned from an academic-community partnership with autistic self-advocates.* Progress in Community Health Partnerships: Research Education and Action. 011:5(2);143-150

#### Other Publications

**Raymaker, D.M.** (2019). *Reclaiming research for the autistic adult community.* Autism in Adulthood. 1(3):160-161. DOI 10.1089/aut.2019.29005.dra

Nicholas, D., **Raymaker, D.M.**, Hedley, D., Randolph, J.K., Robertson, S.M., Vincent, J. (2019). *An expert discussion on employment in autism*. Autism in Adulthood. 1(3):162-169. DOI 10.1089/aut.2019.290003.djn. All authors contributed equally to this manuscript.

Sale, T., **Raymaker, D.M.**, Rija, M., Gould, V., Wall, C., & Melton, R. (2018). *Mitigating Early Loss of Community Participation in Early Psychosis Services: State of the Science*. Portland, OR: Research and Training Center for Pathways to Positive Futures, Portland State University.

**Raymaker, D.M.** (2018), *Hoshi and the Red City Circuit.* Fort Worth, TX. Autonomous Press, LLC. ISBN 978-1-945955-12-9

**Raymaker, D.M.** (2018). *Heat Producing Entities*. In N. Walker, A.M. Reichart (Eds.). Spoon Knife 3: Incursions (ch.18). Fort Worth, TX. Autonomous Press, LLC. ISBN 978-1-945955-14-3

# Webinars and Workshops

**Raymaker, D.M.** (2020). *Understanding the perspective of the Autistic community in research.* New Jersey Autism Center of Excellence. https://www.youtube.com/watch?v=m5GK7ZgYIrO

**Raymaker, D.M.** (2020). "Having all of your internal resources exhausted beyond measure and being left with not clean-up crew:" Defining, measuring, and understanding autistic burnout. New Jersey Autism Center of Excellence. (link TBD)

**Raymaker, D.M.,** Nicolaidis, C. (2018). *INSAR Summer Institute: Equitable Inclusion of Autistic Adults as Co-Researchers*. International Society for Autism Research. https://www.autism-insar.org/page/Nicolaidis

McDonald, K., **Raymaker, D.M**. (2013). *Strategies for including adults with developmental disabilities in research*. Post-conference workshop. American Association for Intellectual and Developmental Disabilities Annual Meeting, Pittsburgh, PA.

McDonald, K., **Raymaker**, **D.M.** (2012) Ethical Issues in Developmental Disability Research. Webinar sponsored by American Association of Intellectual and Developmental Disabilities. Webinar retrieved from http://aaidd.org/content\_8657.cfm.

# Selected Presentations at Professional Meetings

**Raymaker, D.** *Autistic burnout and community voice*. Invited talk. UC Davis Neurodiversity Summit, November, 2020

**Raymaker, D.** for the Academic Autism Spectrum Partnership in Research and Education, "Having All of Your Internal Resources Exhausted Beyond Measure and Being Left with No Clean-Up Crew": Defining Autistic Burnout. Poster presentation. Annual Meeting of the International Society for Autism Research, Seattle USA, May 2020. (Conference cancelled)

**Raymaker, D.M.,** Scharer, M., Widmer, A., Posadas, D.L., Miller, R., <u>Crespo, C.</u> (2019). *After-EXITO: Community based participatory research to improve alumni transition from an intensive undergraduate research program.* Training, Workforce Development, and Diversity Program Director's Meeting, Rockville, MD. August.

**Raymaker, D.M.**, <u>Nicolaidis, C.</u> (2019) "My physical body and mind started shutting down": Autistic burnout and the costs of coping and passing. Invited talk for pre-meeting on mental health. International Society for Autism Research, Montreal. May.

**Raymaker, D.M.**, Mitchell, A. (2018) *Autism and Skilled Employment*. Paper Presentation. TASH Annual Meeting, Portland, OR. December.

**Raymaker, D.M.** (June, 2018). *Pregnancy, Disability, and Women's Decisions: Including Women with Intellectual Disability and Autistic Women in Research and Discussion Around Pregnancy Decisions.* Paper presentation. American Association on Intellectual and Developmental Disabilities, St. Louis.

**Raymaker, D.M.**, Mitchell, A., McDonald, K., AASIRE team. (June, 2018). *Intersectional Identities and Employment for Autistic Professionals*. Paper presentation. American Association on Intellectual and Developmental Disabilities, St. Louis.

Nicolaidis, C., **Raymaker, D.M.,** AASPIRE team. (May, 2018). *Including Autistic Adults in Research to Develop and Evaluate Services Interventions: Lessons from Long-Standing Academic-Community Partnerships*. Poster Presentation. International Society for Autism Research, Rotterdam.

**Raymaker, D.M.**, Scharer, M., Nicolaidis, C., AASPIRE team. (May, 2018). *Narratives of Autism and Skilled Employment: Barriers, Facilitators, and Considerations in Professional Settings*. Poster Presentation. International Society for Autism Research, Rotterdam.

**Raymaker, D.M.**, Sale, T., Valeria, M., Caruso, N., Gould, V. (March, 2018). *Empowerment of Individuals Experiencing Early Psychosis through Community-Based Participatory Research and Technology: Lessons Learned from EASA Connections.* Paper presentation. 31st Annual Research & Policy Conference on Child, Adolescent, and Young Adult Behavioral Health, Tampa.

**Raymaker, D.M.**, Kripke, C. (March, 2018). *The AASPIRE Healthcare Toolkit*. Invited paper presentation. Developmental Disabilities: Update for Health Professionals, San Francisco.

**Raymaker, D.M.** (2017) *Improving health outcomes for autistic people: AASPIRE's work with the healthcare toolkit.* Research Symposium. Autism-Europe 11<sup>th</sup> International Congress. Edinbourgh, UK.

**Raymaker, D.M.**, Nicolaidis, C., Oschwald, M., Ashkenazy, E. (2016) *Inclusive Research at Portland State University*. Research Symposium. TASH Annual Meeting, Portland, OR.

**Raymaker, D.M.**, Nicolaidis, C., Ashkenazy, E. (2016) *AASPIRE Healthcare Toolkit*. Paper presentation. TASH Annual Meeting, Portland, OR.

**Raymaker, D.M.**, Nicolaidis, C., Ashkenazy, E., MacDonald, K.E. (2016) *Inclusive Research Workshop*. Wednesday workshop presentation. TASH Annual Meeting, Portland, OR.

**Raymaker, D.M.** (2014). *Relationships and Holism.* Invited speaker. Love and Autism Conference. San Diego, CA.

**Raymaker, D.M.** (2013). Leveraging the dynamics of science, policy, and community for systems change. Paper presentation. Society for Chaos Theory in Psychology and the Life Sciences Annual Meeting, Portland, OR.

**Raymaker, D.M.**, McDonald, K., Stack, E. (2013). *Partnering with people with developmental disabilities to address violence: A community based participatory research project.* Paper

presentation. American Association for Intellectual and Developmental Disabilities Annual Meeting, Pittsburgh, PA.

**Raymaker, DM**., Nicolaidis, C., Baggs, A., Boisclair, W.C., Kripke, C., Ashkenazy, E., McDonald, K., Erikson, K., Tedlow, M. (2012). Getting the Most out of Healthcare. Workshop. Autreat, Johnstown, PA.

**Raymaker, D.M.**, (2011, March) Nothing about us without us: partnering with autistic adults to improve healthcare. Paper presentation. Developmental Disabilities: Update for Health Professionals, San Fransisco, CA.

**Raymaker, D.M.**, McDonald, K., Perry, A., Patka, M., Kidney, C., Stack, E., Nicoladis, C. (2011). Including adults with intellectual and developmental disabilities in research: methods and ethics. Paper presentation. National Multicultural Conference & Summit, Seattle, WA. \*all authors contributed equally to the presentation

**Raymaker, D.M.**, Ashkenazy, E., & Nicolaidis, C. (2010) Community-based participatory research. Paper presentation. Family Medicine Education Consortium NE Region Meeting & Residency Fair, Hershey, PA.

**Raymaker, D.M.**, & Nicolaidis, C. (2010). The dynamics of autistic-academic partnerships. Paper presentation. Critical Autism Studies Workshop, Ottawa, Canada.

Nicolaidis, C., **Raymaker**, **D.M.** (2010, May). Strategies for effective collaborations with geographically-dispersed communities and people with disabilities. Paper presentation. Community Campus Partnerships for Health Annual Conference. Portland, OR.

**Raymaker, D.M.**, & Ashkenazy, E. (2009, June). Uniquely speaking out: self-advocacy for non-standard communicators. Paper presentation. Oregon Disability Megaconference, Portland, Oregon.

McDonald, K., **Raymaker, D.M**., Robertson, S., & Nicolaidis, C. (2008, May). Participatory action research with disabled adults: advancing scientifically sound, socially relevant, ethical research. Paper presentation. American Association for Intellectual and Developmental Disabilities Annual Meeting, Washington, DC.

#### Presentations in Community and Practice Settings

**Raymaker, D.M.** (2019). Autism 206: Transition to Adulthood: "My physical body and mind started shutting down": Autistic burnout and the costs of coping and passing. Seattle Children's Hospital Autism 200 Series invited lecture.

https://www.seattlechildrens.org/health-safety/keeping-kids-healthy/development/autism-200-series/

- 2019 2019 Early Childhood Conference presented by Parent Child Preschools Organization. 16 March, 2018. Clackamas High School –*The Fabulous Diversity of Brains* – Invited workshop
- 2018 2018 Washington Autism Advisory Council Meeting: Improving Health through Trauma-informed Approaches for Individuals with Autism Spectrum Disorders and other Developmental Disabilities, their Families and Caregivers professional expert panelist and guest speaker
- 2018 Portland State University Culturally Responsive Symposium *Accessible Activist Spaces* Presented in collaboration with the Disability Alliance student group
- 2018 Oregon Pediatric Therapists Special Interest Group Neurodiversity: Rethinking Autism

## **Honors, Grants, and Fellowships**

## **Current Research Support**

PI Name: Christina Nicolaidis, Portland State University

Supporting Agency: National Institute of Mental Health Award: R01MH121407

Title: Measuring Health, Function, and Social Well-being in Adults on the Autism Spectrum

Performance Period: 9/1/2019-8/31/2024

**Role**: Co-investigator

**Time Commitment:** 1.2 calendar **Level of Funding:** \$504,625

**Project's Goals:** The objective of this proposal is to use a CBPR approach to create and test a package of patient-reported outcome measures that can be used to evaluate the effectiveness of services interventions for autistic adults across multiple real-world settings.

PI Name: Dora Raymaker, Portland State University

**Supporting Agency: OCTRI** 

Title: Community based participatory research to explore employer training in support of

autistic professionals

Performance Period: 7/1/2019 - 6/30/2021

Role: PI

Time Commitment: FTE .75 Level of Funding: \$133,584

Project's Goals: Career development award to understand how to shift workplace culture to

create more autism-friendly work environments.

## <u>Selected Completed Research Support</u>

PI Name: Dora Raymaker, Portland State University

**Supporting Agency:** OHSU-PSU Collaborative Research Program **Title:** Pilot study on autistic adult burnout and suicide behavior

**Performance Period:** 9/28/2018 - 9/30/2019

Role: PI

Time Commitment: FTE .2

Level of Funding: \$50,000

**Project's Goals:** Exploratory mixed-methods pilot to begin characterizing autistic burnout and developing a measure for use in a larger NIH-funded grant to examine autistic burnout and suicidal behavior.

**PI Name:** Dora Raymaker, Portland State University **Supporting Agency:** NIH, **Award:** 1R21MH112038-01

**Title:** Autism and Skilled Employment: An Exploratory Study to Inform Future Intervention

**Performance Period:** 12/14/2016 - 11/30/2018

Role: PI

Time Commitment: 3.6 calendar months

Level of Funding: \$417,285

**Project's Goals:** This study first uses qualitative methods to better understand autistic people's experiences with skilled employment, and then convenes a series of workgroups, as well as additional qualitative interviews, to develop an intervention plan.

**PI Name:** Christina Nicolaidis, Portland State University **Supporting Agency:** NIH, **Award:** 1R34MH111536-01

Title: Health System Integration of Tools to Improve Primary Care for Autistic Adults

**Performance Period:** 1/1/2016 - 12/31/2018

Role: Co-Investigator

Time Commitment: 1.2 calendar months

Level of Funding: \$690,072

**Project's Goals:** The project will use a CBPR approach to 1) understand how best to integrate the AASPIRE Healthcare Toolkit into diverse health systems, 2) collect robust efficacy data, and 3) explore potential mechanisms of action in preparation for a large hybrid effectiveness-implementation cluster randomized controlled trial.

PI Name: Janet Walker, Portland State University

**Supporting Agency:** DHHS/Administration for Community Living/National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), **Award:** 90RT5030

Title: Pathways to Positive Futures - EASA Connections

**Performance Period:** 4/1/2015 - 9/29/2019 **Role:** PI for EASA Connections portion of project

**Time Commitment:** 3.6 calendar months **Level of Funding:** \$875,000 (per year)

Project's Goals: A developmental project to create and pilot test a series of peer-created and

peer-led Internet-based resources for youth experiencing early psychosis.

PI Name: Carlos Crespo, Portland State University (Dora Raymaker, sub-project award PI)

Supporting Agency: NIH BUILD EXITO, Award: 5UL1GM118964-03

Title: After-EXITO

**Performance Period**: 9/14/2019 - 6/30/2019

**Role:** Sub-project PI **Time Commitment:** .09

Level of Funding: \$22,000

**Project's Goals:** The goal of this project is to use a community based participatory research approach to help understand, develop, and pilot a plan for post-EXITO support of scholars.

PI Name: Carlos Crespo, Portland State University (Dora Raymaker, EXITO Pilot Award PI)

**Supporting Agency:** NIH BUILD EXITO, **Award:** 5UL1GM118964-03 **Title:** EXITO Pilot Award: Narratives of Autism and Skilled Employment

**Performance Period**: 7/22/2016 - 6/30/2017

Role: EXITO Pilot Award PI

Time Commitment: 2.85 calendar months

**Level of Funding:** \$74,250

**Project's Goals:**\_The purpose of the proposed study is to use qualitative methods to better understand the employment experiences of adults on the autism spectrum, in order to inform a future intervention to increase successful employment.

**PI Name**: Mary Oschwald, Portland State University **Supporting Agency:** NIH, **Award**: 1R21HD078830-01A1

Title: Pregnancy and Support Services for Women with Developmental Disabilities

Performance Period: 8/8/2014 - 10/31/2016

**Role:** Co-Investigator

Time Commitment: 3.84 calendar months

**Level of Funding:** \$415,800

**Project's Goals:** Community-engaged qualitative project to understand and identify experiences related to pregnancy from women with intellectual disability and women on the autism spectrum, and to develop accessible, targeted women's health resources.

**PI Name**: Christina Nicolaidis, Portland State University **Supporting Agency:** NIH, **Award**: 7R34MH092503-03

Title: Partnering with Autistic Adults to Develop Tools to Improve Primary Healthcare

**Performance Period**: 6/1/2011 – 4/30/2015

**Role:** Project Coordinator and Co-PI. **Time Commitment:** 3.13 calendar months

Level of Funding: \$630,429

**Project's Goals:** Series of studies, using a community-based participatory research approach, to develop and evaluate an interactive healthcare toolkit for adults on the autistic spectrum and their primary care providers.

PI Name: Rosemary Hughes, University of Montana Rural Institute

Supporting Agency: Centers for Disease Control and Prevention, Award: DHHS

5U01DD000231-03

**Title:** Partnering with People with Developmental Disabilities to Address Violence.

**Performance Period:** 2009 - 2012 **Role:** Steering Committee Member.

**Level of Funding:** \$1,050,000

**Project's Goals:** Community Based Participatory Research study to investigate the relationship between violence, health, and disability for individuals with developmental disabilities.

PI Name: Christina Nicolaidis, Oregon Health & Science University

Supporting Agency: Oregon Clinical and Translational Research Institute (NIH-Funded CTSA),

**Award:** UL1 RR024140

Title: Community-Based Participatory Research to Improve the Healthcare of Autistic Adults.

**Performance Period:** 6/1/2009 to 5/1/2010.

Role: Project Coordinator and Co-PI.

Level of Funding: \$30,000

**Project's Goals:** Mixed methods study, using a community-based participatory research approach, to compare the healthcare of autistic adults, adults with disabilities, and adults without disabilities, and to explore ways to improve healthcare for autistic adults.

#### Other Research and Other Creative Achievements

Founding Co-Director, Academic Autism Spectrum Partnership in Research and Education, 2006-current

<u>Awards</u>	
2019	Service to the Self Advocacy Community – Autistic Self Advocacy Network (ASAN)
2018	Student and Early Career Academic Excellence Scholarship – American Association
	on Intellectual and Developmental Disabilities (AAIDD)
2014	Student Award - AAIDD
2010	Progress Toward Novel Federal Funding - OCTRI

## **Research Intervention Products**

**AASPIRE Healthcare Toolkit** – An online, interactive resource for adult autistic patients, supporters, and healthcare providers for improving healthcare. https://autismandhealth.org Created via NIMH grants 7R34MH092503-03

**Pregnancy, Disability, and Women's Decisions** – An eight-part video series for women with intellectual disabilities and autistic women around pregnancy decision-making. https://pregnancyanddisability.org Created via NIH grant 1R21HD078830-01A1.

**EASA Connections** – A peer-directed, multimedia resource for new participants in the Early Assessment and Support Alliance (EASA) early psychosis program. http://easaconnections.org/index.php Created via NIDILRR grant 90RT5030

## Selected Invited Guest Lectures

2020 - West Virginia University Center for Excellence in Disabilities Ability Grand Rounds – Improving Healthcare for Adults on the Autism Spectrum

- 2018 PSU-OHSU School of Public Health OHSU Brain Institute, and Doernbecher Children's Hospital *Public Health Portland Style #9 Neurodiversity: Rethinking Autism*
- 2018 OHSU Autism Seminar Series, Department of Psychiatry / Institute of Developmental Disabilities Pediatrics *Narratives of Autism and Skilled Employment*
- 2017 Portland State University COUN 595 Contemporary Issues and Applications in Rehabilitation Counseling *Autism and Skilled Employment*
- 2017, 2015, 2013, 2011 Systems Science Seminar Participatory Research: Science and Social Change (2011), Social, Political, and Ethical Considerations with Minority Representation in Knowledge Production (2013), The Learning Organization and Power (2015), Demystifying the Peer-Reviewed Publication Process (2017)
- 2013, 2014 Portland State University SW 510/610 Interdisciplinary Seminar on Research Methods in Social Determinants of Health Social, Political, and Ethical Considerations with Minority Representation in Knowledge Production
- 2012, 2013 Syracuse University Graduate Seminar on Disability and Health *Systems Change* and Partnering with Autistic Adults to Improve Healthcare
- 2013 Portland State University PSY 610 Community-based Participatory Research Methods Community Based Participatory Research
- 2010 2013 Oregon Health and Science University HIP 533 Community Based Research Community Based Participatory Research: Theory and Implementation
- 2008 Psychology 321: Portland State University Research Methods in Psychology Modeling and simulation methods for behavioral science.

# Other Community Outreach Achievements

Advocacy and Policy	
2018 -	Interagency Autism Coordinating Committee (IACC) Health Workgroup
2009 - 2016	Healthcare Subcommittee Member, Oregon Commission on Autism
	Spectrum Disorder
2011 - 2013	Member, The Autistic Self Advocacy Network
2009 - 2011	Full Member, Oregon Commission on Autism Spectrum Disorder
2008 - 2011	Board of Directors, The Autistic Self-Advocacy Network
2008 - 2013	Member, Oregon Self Advocacy Coalition (formerly Self Advocates
	As Leaders)
2007 - 2009	Member at Large, Board of Directors, Portland Asperger's Network

## Podcasts:

Steward, R., Nicolaidis, C., Raymaker, D. Autism Matters Podcast Number 28: Robyn Steward interviews Dora Raymaker and Christina Nicolaidis, co-founders of AASPIRE, to discuss their practice-based guidelines for the inclusion of autistic adults in research as coresearchers and study participants. Posted June 2019. https://journals.sagepub.com/page/aut/podcasts

Lory, B., Nicolaidis, C., Raymaker, D. *Neurodiverse Working Relationships, with Christina Nicolaidis, MD, MPH and Dora Raymaker, Ph.D. of AASPIRE.* Spectrumly Speaking ep. 30. Available at: http://differentbrains.org/neurodiverse-working-relationships-christina-nicolaidis-md-mph-dora-raymaker-ph-d-aaspire-spectrumly-speaking-ep-30/

Han H, Nicolaidis C, Raymaker D. Beyond the Manuscript 9.2: Community based participatory research to adapt health and violence measures for use by people with developmental disabilities. Progress in Community Health Partnerships: Beyond the Manuscript. 2015. Available at:

https://www.press.jhu.edu/journals/progress\_in\_community\_health\_partnerships/multi media.html. Accessed September 29, 2015.

## Other Media Presence

Meet the Autistic Scientists Redefining Autism Research. Spectrum News; June 10, 2020 https://www.spectrumnews.org/features/deep-dive/meet-the-autistic-scientists-redefining-autism-research/

'Autistic voices should be heard.' Autistic Adults Join Research Teams to Shift Focus of Studies. Science; April 29, 2020 <a href="https://www.sciencemag.org/news/2020/04/autistic-voices-should-be-heard-autistic-adults-join-research-teams-shift-focus-studies#">https://www.sciencemag.org/news/2020/04/autistic-voices-should-be-heard-autistic-adults-join-research-teams-shift-focus-studies#</a>

## Solicited expert interview:

https://www.ashclinicalnews.org/features/rewriting-informed-consent/

#### Related to the autistic burnout study:

Source	Link
Thinking Person's Guide	http://www.thinkingautismguide.com/2019/08/autistic-burnout-
to Autism	interview-with.html
Transforming Autism	
Project	https://youtu.be/yPvsLZXU1rw
Autism in Adulthood	
press release	http://email.liebertpub.com/q/1m7rb70nXKAnp4Za5Zci/wv
	https://www.reddit.com/r/science/comments/gyb96a/study_autistic_b
Reddit	urnout_is_a_syndrome/

Related to the autism and employment study:

Source	Link
Oregon Public	
Broadcasting	http://www.opb.org/radio/programs/thinkoutloud/segment/autism-work-
(OPB)	accommodation-employee-portland-state/
	http://katu.com/news/local/portland-state-professor-with-autism-wins-
KATU	467000-grant-to-study-autism-in-the-workplace
Fox 12	
Reddit Science	https://www.reddit.com/r/science/comments/5wj58r/science_ama_series_
Ask Me Anything	im_dora_raymaker_an_assistant/
	https://www.pdx.edu/news/autistic-psu-researcher-wins-467000-study-
PSU press	autism-workplace
	http://relay.foundation.pdx.edu/rel@ycampaigns/campaign2669/template.j
	sp?campaignId=2669&recipientId=36136989&mpLogId=45432&test=false
	http://portlandtribune.com/pt/9-news/350889-228575-psu-researcher-
Portland Tribune	gets-grants-to-study-autistic-employees-in-the-workplace

Work with the Disability Alliance student group: https://psuvanguard.com/fourth-annual-culturally-responsive-symposium-highlights-effective-activism/

# **Professionally-related Service**

2018 – current Associate Editor of refereed journal Autism in Adulthood - Christina Nicolaidis, ed.

## Scientific Grant Review:

2018 – current Organization for Autism Research

2018 National Institute on Disability, Independent Living, and Rehabilitation

Research

# Ad-hoc Manuscript Review:

Autism in Adulthood

Autism: The International Journal of Research and Practice

Research in Autism Spectrum Disorder

Action Research

Journal of General Internal Medicine
Systemic Practice and Action Research

## **Professional Organizations**

Member: American Association on Intellectual and Developmental Disabilities (AAIDD)

Member: International Society of Autism Researchers (INSAR) Founding Member: INSAR Autistic Researcher Committee (ARC)