

# NCATS Wow! Factor Story

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## KL2 scholar puts Autistic Burnout on research map

### SUMMARY OF PUBLIC HEALTH IMPACT

A team of researchers led by Dr. Dora M. Raymaker, one of few openly autistic researchers, used a community-based participatory research (CBPR) approach to conduct an inaugural study on autistic burnout. Findings draw attention to the syndrome, long recognized by autistic people but not formally investigated, and will inform future research, prevention strategies, and interventions.

### BACKGROUND

Autistic burnout can contribute to executive functioning declines, depression, self-harm and suicidal ideation. Despite these impacts, and the fact that suicide is the leading cause of death among autistic adults without intellectual disability, research on autistic burnout was nonexistent. OCTRI KL2 scholar and BUILD EXITO Round 1 Pilot Project recipient, Dora M. Raymaker, PhD, used a community-based participatory research (CBPR) approach to conduct the first-ever study on the topic. This resulted in a landmark paper characterizing autistic burnout and defining it as a phenomenon distinct from occupational burnout or clinical depression. In addition to laying the groundwork for finding ways to relieve or prevent burnout, this paper gave a voice to the autistic community regarding their own health needs and highlights the importance of using CBPR methods in understanding and defining the needs of populations who are typically underrepresented in research. Data from this study contributed to an R34 application, authored by mentor and collaborator Christina Nicolaidis, MD, MPH, an OHSU Internal Medicine physician and School of Social Work professor at Portland State University, that will fund an interventional study working with employers to develop workplace practices to relieve or prevent autistic burnout. Drs. Raymaker and Nicolaidis were featured in *Science* for their CBPR study.

### NIH GRANT SUPPORT, INCLUDING OTHER NIH INSTITUTES AND CENTERS

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### OTHER COLLABORATORS

- Christina Nicolaidis, MD, MPH, Adjunct Associate Professor of Medicine, Division of General Internal Medicine and Geriatrics, School of Medicine, Oregon Health & Science University; Professor, School of Social Work, Portland State University

### REFERENCE ARTICLES/LINKS

DM Raymaker, AR Teo, NA Steckler, B Lentz, M Scharer, AD Santos, SK Kapp, M Hunter, A Joyce, and C Nicolaidis (2020). Having All of Your Internal Resources Exhausted Beyond Measure and Being Left with No Clean-Up Crew: Defining Autistic Burnout. *Autism in Adulthood*. Jun 2020.132-143. <http://doi.org/10.1089/aut.2019.0079>

Emily Willingham (2020). Autistic voices should be heard: Autistic adults join research teams to shift focus of studies. *Science*, 29, 2020. [doi:10.1126/science.abc5398](https://doi.org/10.1126/science.abc5398)